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REDEFINING ONE'S CAREGIVING ROLE:

PLACING A FAMILY MEMBER WITH ALZHEIMER'S DISEASE IN A LONG TERM CARE FACILITY

BY

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled *Redefining One's Caregiving Role: Placing a Family Member With Alzheimer's Disease in a Long Term Care Facility* submitted by Moira J. Bazin in partial fulfillment of the requirements for the degree of Master of Nursing.

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Abstract

Persons with Alzheimer's disease receive most of their care from family members in the community. However, many families eventually face the decision of whether or not to place their ill relative in a long term care facility. Understanding of families' experience during this time remains unclear in the research literature. Using a grounded theory approach, this qualitative study identifies "redefining one's caregiving role" as the process of making the transition from caregiving in the community to caring for a relative in a long term care facility. Findings are based on interviews with ten family caregivers who had placed a relative with Alzheimer's disease in long term care within the past 13 months. Prior to placement caregivers experienced the phases of "realizing" and "preparing with uncertainty". After placement, caregivers moved through the phase of "finding the way", which involved the stages of "coming to terms" and "redefining one's caregiving role", before entering the final phase of "carrying on with ongoing change".

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CHAPTER I: INTRODUCTION

Although indications of the presence of Alzheimer's disease can be traced as far back as 500 BC in Greek society, a German neurologist, Alois Alzheimer, first brought the disease to light in 1906 when he presented the case of a middle aged woman suffering from dementia (Ross, 1987). Yet it is only since 1980 that nursing researchers have begun to investigate issues associated with care of someone with Alzheimer's disease (Maas & Buckwater, 1991).

The cause of Alzheimer's disease is unknown and as yet there is no cure. In 1991, 5.1% of seniors in Canada, or 161,000 persons, were afflicted with Alzheimer's disease, the fourth most common cause of death for seniors behind cancer, heart disease, and stroke. By the year 2011, it is estimated this number will rise to 314,000 persons (National Advisory Council On Aging, 1996). Gruetzner (1992) states as many as 58% of persons living in nursing homes in the U. S. are believed to be afflicted with Alzheimer's disease and the disease can present itself in persons as young as forty years of age. For those afflicted with Alzheimer's disease before age 60 the disease takes on a rapid course resulting in death within three to five years. For those afflicted in their later years the disease progresses more slowly, often over ten or more years. The disease prevalence rises from one percent in the group 65-74 years of age, to 6.9 percent in those aged 75-84, and to an alarming 26 percent in those 85 years and older (National Advisory Council on Aging, 1996). Of the seventy conditions known to cause dementia, 66% of cases are a result of Alzheimer's disease (Office of Technology Assessment, 1987).

Symptoms of this disease often include memory deficits, language difficulties, apraxia and impaired visuospatial skills, poor judgment, self-neglect, behavior problems, and in later stages, physical deterioration (Handy, Turnbull, Norman, & Lancaster, 1990). As the size of the aged population continues to grow implications of this disease for families will be many. As Ross (1987) states, it is the "disease of the century", a "silent epidemic" which has greater impact on family and society than many other maladies.

Alzheimer's disease is a major concern for many in the health care sector. For those afflicted, as well as the spouse and family members, this disease is tragic. Watching a family member regress and become a different person, one that does not remember you or your shared memories, can be heartbreaking. Family caregivers are deeply affected by this experience and have been called the "hidden victims" of this disease (Nick & Douglas, 1991). Many living this experience are committed to providing quality care even under the most difficult circumstances. However many also find themselves having to consider placing their family member in a long term care facility. This study examines the transition experienced by the family caregiver, before, during and after the care recipient moves from the community into a long term care facility.

Purpose

The purpose of this study is to uncover the transition experienced by family caregivers of persons with Alzheimer's disease from caregiving in the community to caregiving when the care recipient has entered a long term care facility. Other questions addressed in this inquiry include:

What are the events and experiences of family caregivers leading to the decision of placement? What factors influence this transition? How did the caregiver's caregiving change after the care recipient was placed in a long term care facility?

Definition of Terms

Family Caregiver

In this study a family caregiver refers to an individual who is responsible for providing assistance and support, beyond what is ordinarily exchanged in the family role relationship, in order to meet the needs of a family member with Alzheimer's disease. Caregivers will be included who made the decision to place a family member and did so, for the first time, within the year prior to entering the study.

Placement

Placement refers to the admission of a person to a long term care facility on a permanent basis. Placement involves a process including an assessment of the individual by a home care coordinator, and the arrangement of suitable permanent care services by the local health authority. The time frame of this process varies depending upon the urgency of the individual's situation and bed availability.

Long Term Care Facility

In this study a long term care facility refers to a residential facility providing formal care to an individual with chronic care needs on a permanent basis. Facilities providing this service can include: institutional facilities with specialized care units, nursing homes, assisted living settings, or group homes. Similar terms that may also be used in this study are "long term care setting", "institution", "institutional setting".

Alzheimer's Disease

The term Alzheimer's disease in this study refers to the incurable, degenerative disease known by that name. Major symptoms of the disease include progressive loss of mental faculties and speech defects. If this term was used by the caregiver to describe the care recipient's condition it was assumed that the care recipient was afflicted with this disease.

CHAPTER II: LITERATURE REVIEW

In this chapter a review of literature is presented which examines caregivers' experience with placement of a relative with Alzheimer's disease in a long term care facility. The literature will first be examined in the general areas of family caregiving for a relative with Alzheimer's disease and placing a relative in a long term care facility. Then the research addressing family caregiving and placement of a relative with Alzheimer's disease in a long term care facility will be discussed.

Family Caregiving for a Relative with Alzheimer's Disease

The majority of those afflicted with Alzheimer's disease live at home, and it is estimated that the family provides more than 80% of care (Dhooper, 1991). A national Canadian survey (1991) found that 98% of persons with dementia have a caregiver, 37% of caregivers of persons with dementia living in the community were spouses, 42 % were children of the care recipient, and 23% were another family member or friend. In institutional settings, 13% of caregivers were spouses, 64% were a child, and 23 % were a family member or friend of the dementia patient (The Canadian Study of Aging and Health Working Group, 1994). On average, caregivers of persons with mild to moderate dementia provide 3.2 hours of care per day, and those caring for persons with severe dementia, provide 8.06 hours of care daily (National Council on Aging, 1996). Another study, done in the US (Ashensel, Pearlins, Mullin, Zarit and Whitlatch, 1995) found that the mean amount of time that caregivers provided in home care was 6.5 years. As these figures indicate, caregiving involves a great investment of time, often over many years.

When a member of a family is diagnosed with Alzheimer's disease, the impact is felt throughout the family and disrupts previously stable patterns in the family system (Biegel, Sales, & Schultz, 1991). Family caregiving roles vary greatly depending on the onset of the disease, whether the disease is progressive, and whether it is fatal or nonfatal (Biegel et al., 1991). In a progressive disease such as Alzheimer's disease, the person's disability increases over time, requiring the caregiver to continually adapt and increasing the risk of caregiver exhaustion. A critical factor in the family's ability to adapt is whether the disease is fatal, as is the case in Alzheimer's disease. Families may experience anticipatory grief, and what Rolland identifies as the dilemma of wanting to be closer, yet wanting to pull away (Biegel, Sales, & Schulz, 1991, p. 23).

Spousal caregivers may be at particular risk for health and financial difficulties due to their own advancing age. In a study by Wright (1994), initially spousal caregivers of persons with Alzheimer's disease and noncaregivers reported the same level of health. However after two years the caregiver group reported lower levels in comparison to the noncaregiver group. In a large Canadian study that compared caregivers of persons with dementia to caregivers of non demented persons in the community, depressive symptoms were twice as common among caregivers of persons with dementia (The Canadian Study of Health and Aging Working Group, 1994). Despite this great toll, caregivers persevere and invest years of physical and emotional energy in caring for their family member.

Family Caregiving and Placing a Relative in a Long Term Care Facility

Historically families cared for those in need and the sick, disabled, poor, or elderly relied on the family, whose duty it was to provide care. Those without family

assistance, who were impoverished, ill, or feeble, were frequently sent to institutions. By the Second World War institutional settings had expanded, become more specialized, and offered improved care (Forbes, Jackson, & Kraus, 1987).

For many families, institutionalization is still seen as a last resort, to be considered when all else fails (Pruchno, Micheals, & Potashnik, 1990). In a study involving 589 family caregivers, attitude towards placement was found to be as important as the elder's health and the caregiver's level of stress in determining who would be placed (Deimling & Poulshock, 1985). Society still views placement as a deviant act (Matthieson, 1989). But, due to the progressive nature of Alzheimer's disease, a point is often reached when care can no longer be provided in the home and placement is required.

Placement involves months of planning and organizing, and may precipitate a period of crisis (Buckwater & Hall, 1987). For the elderly individual placement represents a transition to what is often seen as their last home. Anticipating the event can be stressful for family members, and once placement occurs adaptation to a new environment begins.

Chenitz (1983), using a grounded theory approach, examined how elders adjust to a move to a nursing home and found that acceptance of the move occurred when one or more of the following basic conditions were satisfied: desirability, legitimization, voluntary nature, and reversibility. If one or more of these basic conditions was not present, resistance occurred. Brooke (1989) identified four phases in the process of adjusting to living in a nursing home which are disorganization, reorganization, relationship building, and stabilization. Ninety three percent of participants had

reached stabilization within eight months of admission. Wilson (1997) identified three phases involved in the transition adjustment of elders entering a nursing home: overwhelmed phase, adjustment phase, and initial acceptance phase. The persons whose entry was planned moved through to "initial acceptance" more quickly than those whose admission was unplanned.

For many elders a move to a new location is a stressful event, that has been identified as "relocation stress syndrome". This syndrome involves "physiologic and/or psychosocial disturbances as a result of transfer from one environment to another". It is characterized by change in environment, anxiety, apprehension, increased confusion, depression, and loneliness. Other contributing factors include: past, concurrent, and recent losses, lack of an adequate support system, the degree of environmental change, and a decreased physical and or psychosocial health status (Manion & Rantz, 1995, p. 108). In a previous study done by Miller and Rantz (1987), 23% of the population in a 328 bed nursing home had a current diagnosis of translocation syndrome or relocation stress syndrome, and for an additional 15% this syndrome was resolved.

Bower (1988) explains that little literature in the past has focused on family caregiving after placement has occurred, as it has generally been viewed as the end of family caregiving responsibilities. However this view is proving to be incorrect, as placement does not break family ties or end caregiving responsibilities. Bower found that families engaged in four types of preservative caregiving or "care which is engaged in to maintain the older person's self" within a nursing home (p. 362, 1988).

The four types include: maintaining family connectedness, dignity, hopes, and control over the environment.

In a qualitative study, Dellasega and Mastrian (1995) identified and described stressors felt by family members during and after making the decision to place an elderly family member in a care facility. Several themes were identified which influenced the difficulty of the decision. One theme "singularity", as family members felt alone in making the decision. Another theme, "escalated crisis", evolves from a lack of preparation for and acknowledgment of the situation. The theme of "conformity" involves a need to maintain an idealized view of themselves as caregiver, which is often difficult since admitting the care recipient to long term care may be considered contrary to this view. The last theme is "peer validation". Validation is sought with family and friends to confirm that they made the right decision. Dellasega and Mastrian explain that once placement has occurred family members report emotional turmoil with feelings of sadness, loneliness, anger, resentment, and relief. Those in least turmoil reported ambivalence about the placement decision, and all found they needed to redefine their caregiving role (p. 132, 1995). In Fink and Picot's (1995) study, African-American and European-American caregivers were interviewed regarding their experiences with recently placing a family member in a long term care facility. She explains that although the caregivers initially had a negative view of nursing homes, they found it to be a more positive experience than they had expected. Three major themes identified during the post placement experience were: "relief and reinvolvement", "regrets and losses", and "the continuing caregiver role". Few differences were found between African-American and European-American caregivers.

In both cultures there is a strong expectation that female members of the family take on the role of caregiver.

Common reactions of family members, surrounding placement of a relative, are guilt and grief. Johnson and Werner (1982) attempted to measure the degree of guilt felt by family caregivers involved in placing a loved one and found guilt scores that were below the neutral point. They concluded that the persons surveyed were comfortable with their decision. However in Matthiesen's (1989) grounded theory study, involving interviews with daughters who had placed their mothers in a nursing home, a consistent theme of unresolved guilt was found; sometimes initiated even before the placement decision had been made. Another response Matthiesen found was a feeling of loss. The daughters indicated that they felt that the transition from in-home to nursing home was even more difficult for them than for their mothers. Matthiesen adds that because the mother is still alive and is a reminder of the loss, the grief felt is different than that felt when someone is lost due to death. Interestingly, the grief was most acutely felt in those daughters whose mothers were deteriorating mentally.

Placement of a spousal partner means a separation of the couple thus impacting the marital relationship. To describe this phenomenon Rollins, Waterman, and Esmay (1985) use the term "married widowhood". Ade-Ridder and Kaplan (1993) examined the wife's role once placement of a husband had occurred. With placement, the couple separated and wives often go through a role transition. Some may continue to see themselves as part of a "couple" or as a "we", and others lose the feeling of couplehood, and think of themselves in terms of "I". They contend that how a wife

interacts with her husband in the nursing home depends upon the transition experienced. In a study examining wives' task performance after placement, Ross, Rosenthal, & Dawson (1997) found on average, that wives carried out 10 tasks one month after placement, and 11 tasks after nine months. Dempsey and Pruchno (1993) state role theory, "suggests that behaviors associated with a given role will be the result of cultural norms and values, socialization, and individual personality, as well as constraints of situational factors which allows for variation within a general set of role requirements" (p. 128).

Family Caregiving and Placement in a Long Term Care Facility of a Relative With Alzheimer's Disease

In an attempt to gain an understanding of family caregiving and the transition of family members with Alzheimer's disease to formal care, all identified studies of relevance to this topic were examined. The quantitative studies found will be summarized under several categories according to the placement issues they addressed. These categories include: characteristics of caregivers seeking placement, factors influencing placement, factors delaying placement in long term care, and the transition to long term care from the community. In addition, several qualitative studies were found to be relevant. Because of the nature of these studies they will be summarized individually.

Characteristics of Caregivers Seeking Placement

Five studies were found that surveyed caregivers on whether they desired to place the care recipient or whether they did not (Morycz, 1985; Gilhooly, 1986; Pruchno, Micheals, & Potashnik, 1990; Aneshensel, Pearlin, & Schuler, 1993; Cohen, Gold,

Shulman, Wortley, McDonald, & Wargon, 1993). Caregivers who indicated a desire to place a care recipient tended to be younger, employed (Gilhooly, 1986), have more dependents (Gilhooly, 1986; Pruchno, et al., 1990) and experience economic strain (Aneshensel et al., 1993). These individuals, in comparison to caregivers not considering placement, reported their health as being worse (Cohen et. al. 1993) experienced greater psychological distress (Aneshensel et al., 1993), and took more mood altering drugs (Pruchno et al., 1990). Also, they reported less enjoyment in the caregiving role (Cohen et al. 1993), more dissatisfaction with help from relatives (Gilhooly, 1986), greater strain and burden (Morycz, 1985, Cohen et. al., 1993, Pruchno et. al., 1990) and increased feeling of role captivity (Aneshensel et. al., 1993). They were also caregivers for a shorter time (Pruchno et. al., 1990).

Caregivers who identified a desire for institutional placement more often expressed this desire if the care recipient was widowed, lived alone, and required more physical energy in the provision of care (Morycz, 1985). Several studies found that the greater the care recipient's cognitive impairment, behavior problems, or incontinence, the greater the desire by the caregiver to consider placement (Cohen et al., 1993; Pruchno et al., 1990). However other studies found no correlation between care recipient characteristics and the caregivers' desire to place the individual in a long term care facility (Gilhooly, 1986; Colerick & George, 1986; Aneshensel et al., 1993).

In a large study done be Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) 51% of caregivers became "very upset" when thinking about the prospect of placement, yet the actual rate of institutional placement was similar to those who reported not being upset when having to consider it. The authors conclude that

although many caregivers do not like the thought of placement they "ultimately accede to the forces pressuring them to do so" (Aneshensel. et al., p. 184, 1995). Cohen et al. (1986) found that of those who indicated a desire to provide care in the home, more than half ended up having to place a care recipient in a long term care facility, possibly during a crisis.

Characteristics of those who actually placed a loved one are similar to those who had a desire to do so. In fact, Morycz (1985) found that the greatest predictor of actual placement was indicating a wish to do so. Those who actually placed a family member tended to be younger, female, employed, have dependents, and be a child, rather than a spouse, of the care recipient (Colerick and George, 1986). Similarly, these caregivers used more services (Cohen et al. 1986; Pruchno et al 1990), and were more likely to use psychotropic drugs, even after placement had occurred (Colerick & George, 1986).

Factors Influencing Placement in a Long Term Care Facility.

Actual placement rates for care recipients with Alzheimer's disease range from 20% over a one year period (Zarit et al., 1992), to 34% after four years (Collins, King, Kokinakis, 1994). Of the care recipients actually placed in the Zarit and Whitlatch (1992) study, 60 % of care recipients had experienced an acute illness requiring hospitalization in the year previous. Chenoweth and Spencer (1986) surveyed the reasons for placement reported by their participants and found that 72% indicated that 24 hour care had become too difficult, and 21% of caregivers became ill. In 18% of cases the caregiver indicated that the care recipient's behavior was the reason for placement and 13% indicated that a doctor had made the recommendation. Some

caregivers gave more than one reason. In a large Canadian study (The Canadian Study of Health & Aging Working Group, 1994), of the caregivers of persons with dementia, 40% listed the major reasons for placement of the care recipient as behavior problems, and feeling overwhelmed, compared to only 15% of non dementia caregivers. Also this study found that 53% of caregivers of persons with dementia living in the community had considered placement, whereas only 11% of caregivers of persons without dementia had done so.

Factors Delaying Placement in a Long Term Care Facility

Because of the emphasis in health care on maintaining individuals in the community as long as feasible, information on factors which delay placement in long term care is useful. However of the studies found, only four focused on interventions that would delay placement of a person with Alzheimer's disease in long term care (Ferris, Steinberg, Shulman, Kahn, Reisberg, 1987; Lawton, Brody, Saperstein, 1989; Mittelman, Ferris, Steinberg, Shulman, Mackell, Ambinder, Cohen, 1993; Collins, King, Kokinakis, 1994).

A respite intervention to delay placement was studied by Lawton, Brody, & Saperstein (1989). They found that after one year, with respite support, caregivers were able to keep a care recipient with Alzheimer's disease in the community 22 days longer, on average, than those not receiving this assistance.

A study (Ferris et al., 1994) (n= 109) of a counseling and support intervention firstly identified precipitating factors which influenced placement with one group and then provided counseling to address those factors to a new sample of 41 caregivers in the community. After six months of individual counseling, home visits, and

involvement in caregiver support groups, only one caregiver, who had serious health problems, placed a relative. The authors note that findings should be viewed with caution as a control group was not included and six months of counseling is relatively short, particularly due to the changing and unpredictable course of the disease. In another study of counseling and support interventions for spousal caregivers (n=206) the control group received routine assistance such as advice and help with resources. The treatment group, participated in support groups and received individual and family counseling on demand. After one year, 24 placements had occurred in the control group and only 11 in the treatment group. The authors conclude, however, that the mechanisms by which the interventions prevented placement are difficult to unravel.

Community service issues are another factor that influence placements and Collins, King, and Kokinakis (1994) addressed issues that occurred three months prior to placement. The sample was comprised of 338 primary caregivers of persons with Alzheimer's disease or dementia living in the community who were surveyed on admission to the study and every 12-15 months over four years. Thirty four percent of the sample placed the care recipient during the study, and 40 % said that the availability of at least one additional service would have delayed placement. However, the majority (60 %) of caregivers indicated that additional services would not have made a difference. The most frequently cited factor in influencing placement was the inability to find a needed service; the second most cited factor was affordability. A significant factor for service use was caregiver employment. The authors conclude, as is supported by Pruchno, Micheals and Potashnik (1990), that focusing on the period

three months prior to placement may not provide an adequate picture as this process may begin long before actual placement.

Transition to Long Term Care from the Community

Several studies were found that addressed family caregivers' transition when their relative enters a long term care facility. In examining the effects of placement on caregivers several studies examined variables such as problems and stressors (Zarit & Whitlatch, 1992), level of burden (Riddick, Cohen- Mansfield, Fleshner, and Kraft, 1992; Barber 1993; The Canadian Health and Aging Study Working Group, 1994), differences in depressive symptoms (Stephens, Kinney, and Ogrocki, 1991), emotions associated with placement (Riddick et al., 1992), and satisfaction with the long term care facility (Chenowith & Spencer, 1986; Maas, Buckwater, Kelley & Stolley, 1991; Riddick et al., 1992).

In an attempt to shed light on the caregiving experience, Zarit and Whitlatch (1992) asked caregivers about problems and stressors they experienced before and after placement. In comparison to their experience prior to placement caregivers reported feeling less tired and pressured with more time for their own activities. Interestingly, no improvements were reported in feelings of well-being. Similarly, Stephens, Kinney, and Ogrocki (1991) found no difference in depressive and somatic symptoms between in-home caregivers and caregivers of persons in a nursing home. For both groups of caregivers the researchers indicate that a great deal of stress could be attributed to the care recipient's memory loss and behavior, which impacted caregiver well being. Stress was higher among those visiting often, in comparison to those who visited less

often, particularly in relation to staff interactions and the logistics of maintaining the caregiving role.

Riddick, Cohen-Mansfield, Fleshner, and Kraft (1992) examined the adaptation of 84 caregivers after recently placing a relative with Alzheimer's disease in a nursing home. Levels of burden were measured by a shorter form of the Burden of Care instrument created by Zarit, Reever, & Bach-Peterson (1980). Participants were asked to complete the instrument twice; first to think back before placement had occurred and then to the present situation. The level of burden was found to be significantly higher before placement in comparison to post placement. A limitation of this study is that it was retrospective, including participants who had placed a family member within the last three years. Nevertheless, the results are similar to findings in the Canadian study (The Canadian Health and Aging Study Working Group, 1994), completed the year previously which also used the Burden of Care instrument developed by Zarit, Reever & Bach- Peterson (1980).

Negative emotions associated with placement were reported in the Riddick et al. (1992) study, and included feelings of sadness, frustration, lack of control, and guilt. Spouses and daughters reported the highest number of negative feelings. Spouses also reported the greatest amount of burden, followed by children, and then those in the "other" category. Barber (1993), in comparing in-home spousal caregivers and nursing home spousal caregivers, found both groups to be similar in level of burden identified and no correlation between objective and subjective burden. Subjective burden was associated with affective balance, relationship strain, and decline in health, whereas objective burden was only correlated with relationship strain. Relationship

strain was correlated with health decline. Caregiving wives in both groups reported more social dysfunction than caregiving husbands.

Several studies that surveyed caregiver satisfaction with nursing home care, found that caregivers indicated they were satisfied (Chenoweth, & Spencer, 1986; Maas, Buckwater, Kelley, & Stolley, 1991; Riddick, Cohen-Mansfield, Fleshner, & Kraft, 1992). Maas et al. (1991) who measured caregiver's perceptions of care in a nursing home over a one year period, using the Family Perceptions Tool developed by Maas & Buckwater (1989), found that family members were satisfied with the overall care, but they were least satisfied with the physical care provided. The family caregivers were most dissatisfied with staff soliciting their help with care, the limited resources available for care, the staff being too busy to give needed care, and the limited amount of patient involvement in activities. A trend to decreasing satisfaction was noted but tapered off in the tenth to twelfth months of data collection for the study.

The findings in these studies indicate that caregivers with a care recipient in long term care continue to experience high levels of psychological distress, especially feelings of depression and anxiety. A great deal of stress relates to the care recipient's memory loss and disorientation. For those caregivers who maintain close contact with their impaired relative, nursing home placement does not signal the end of their concerns (Stephens, Ogrocki, and Kinney, p. 339, 1991; Zarit & Whitlatch, 1992). However the meaning behind these concerns and changes in the caregivers' experience remains unclear.

As can be seen from the array of studies presented in this literature review, family caregiving and placement of a relative with Alzheimer's disease is a complex subject.

The variables being measured in these studies were many and varied depending on the focus of the study. Many studies focused on negative aspects of caregiving such as burden and stress whereas possible positive outcomes for taking on this role and /or looking towards placement were only addressed in one study (Lawton, Brody, & Saperstein, 1989). Most studies used samples of convenience, from agencies directly involved in Alzheimer's disease assessment, care, or support of the caregiver, which could be a source of sampling bias. One large study however used random sampling, collecting data Canada wide (The Canadian Study of Health and Aging Working Group, 1994). Another contacted all persons who had come to their clinic over the last ten years (Ferris, Steinberg, Shulman, Kahn, & Reisberg (1987). The majority of studies involved fairly large sample sizes, at least over eighty subjects. Treatment and control group designs were found only in the studies looking at the effects of specific interventions, such as the provision of counseling services (Mittelman et al., 1993), or respite services in an effort to delay placement (Lawton, Brody, & Saperstein, 1989). In addition, most studies took place within the U.S. where social programs and financial obligations for care are quite different from those experienced by Canadian caregivers. In the Canadian context, entry to long term care placement is based on need rather than resources. This allows researchers to focus more on definitive factors that influence caregiving and the transition to formal care.

Qualitative Research Studies

Several qualitative studies were found that address family caregiving of persons with Alzheimer's disease and placement directly or include concepts or aspects of relevance to placement. The studies that address issues relevant to placement

examined issues including: patterns of mutuality and placement (Hirschfeld, 1983), the decision to institutionalize (Lynott, 1983), the stress felt by spousal caregivers during placement (Morgan & Zimmerman, 1990), the process of caregiving in its entirety, including stage(s) involving placement (Willoughby & Keating, 1991; Wilson, 1989; Lindgren, 1993; Wuest, Ericson & Stern, 1993), and the transition experienced by caregivers from providing in-home care to care in a long term care facility (Duncan, 1992). The latter study, completed in the U.S., will later be discussed in detail as it is highly relevant to the present study.

Based on 60 interviews with caregivers and care recipients, Hirschfeld (1983) identified four caregiving "management relationships patterns" which varied depending on the degree of mutuality in the relationship. The groups exhibiting the four management patterns ranged from those with a high degree of mutuality in the relationship (group 1), to those who experienced no mutuality, and just "survived" (group 4). Those experiencing a higher level of mutuality, were less likely to consider institutional placement.

The decision to institutionalize a family member was addressed in a study involving field observations in three settings (Lynott, 1983). Lynott found that the factors determining placement by caregivers was not arrived at in a definitive manner, and the decision was revisited even after placement had occurred. Also the placement decision was not necessarily related to caregiver's tolerance level as this was open to continual reinterpretation by the caregiver.

In Wilson's (1989) grounded theory study involving 20 family caregivers and their caregiving experience, the basic social psychological problem identified was "coping

with negative choices" where caregiving dilemmas and options represented "different degrees of impossibility" (p. 95). The process was entitled "surviving on the brink", and involved three stages: "taking it on", where the responsibility of caregiving was taken on by the caregiver, "going through it", where the caregiver became established in the role and tried to cope from day to day and most relevant to this discussion "turning it over" where the caregiver gradually decided to turn care over to someone else. Turning it over was a reversal of the previously held negative view of nursing homes. Wilson stated it was a gradual considered process of "giving up control", not identifiable by one problem, but an "ongoing sequence" of problems constantly demanding the time and care of the caregiver, who began to question the impact made on their own life (1989, p. 97). Once the "ultimate negative choice" had been made, the care recipient was placed in a long term care facility.

Lindgren (1993) described phases of what she calls "the caregiving career" in her study involving caregiving spouses. The "caregiving career" involves a trajectory, and begins with the "encounter stage" where the couple receives the diagnosis of Alzheimer's disease and begins to understand the implications and adjust by learning new skills and making changes in life style. Reciprocity declines in the marriage and the spouse begins to see themselves less as a partner and more as a caregiver. Next, the "enduring stage" is marked by a heavy workload for the caregiving spouse who develops routines of care to cope with the situation. Time and energy is limited, so less time is spent with friends. The final stage, which Lindgren (1993) identifies as the "exit stage", is when in-home caregiving concludes or becomes less demanding either

because the care recipient is institutionalized or dies. Decisions and adjustments are made due to changing role demands.

In a Canadian context Wuest, Ericson and Stern (1993) described the changing relationship between the person with Alzheimer's disease and their family caregivers along a continuum of "becoming strangers" where the caregiver/care recipient relationship moves from one of intimacy to alienation, involving dimensions labeled "dawning" , "holding on", and "letting go". The last stage, described as "letting go", involves the decision to relinquish care and place the family member in an institution. Before letting go the caregiver must have "separated" from the care recipient, a gradual process that begins in the dawning stage, and continues until reciprocity is no longer in the relationship. Then a "triggering event" occurs which convinces the caregiver to turn care over to a formal care provider.

Willoughby and Keating (1991) also working within the Canadian context, identified the process of "taking on and relinquishing control" based on interviews from ten family members of persons with Alzheimer's disease residing on a psychogeriatric unit. The five stages identified from a grounded theory analysis include: "emerging recognition" where changes are seen in the care recipient's behavior and emotional distance begins to occur; and "taking control" when a proactive approach is taken in an attempt to achieve and maintain control over care; losing control: when decisions of others are accepted and care is turned over to formal caregivers; adjustment to the psychiatric facility and finally "moving on", when the caregiver can let go and look towards the future, focusing attention on themselves.

However this final stage was seen with only one participant who was interviewed several years after their care recipient's death (Willoughby, 1988).

In an attempt to describe the needs of spousal caregivers of a person with Alzheimer's disease at the time of placement, Morgan and Zimmerman (1990) interviewed ten persons who had recently placed a spouse. From the interviews, five categories emerged that were relevant in reducing stress during the transition of placement. The categories included: emotional support, ability to control the situation, acceptability of the nursing home, acceptance of the situation, and permission/command to make the placement by an authority figure. Locus of control measures were also included. Those caregivers with higher internal locus of control as compared to those with an external locus of control, found control of the situation more helpful in reducing stress during placement. Those with an external locus of control, who tended to expend a great deal of energy trying to "stabilize" the situation, found the permission/command category more helpful.

Duncan, in her doctoral dissertation titled " Alzheimer's Disease Caregivers: The Transition From Home Care to Formal Care" (1992), explored caregivers' transition from providing in-home care to providing care in a long term care setting. Data were examined from two sources: qualitative data from a larger study (Morgan and Duncan 1994) involving 179 family caregivers providing care in the community or in long term care who attended one of 30 focus groups, and interviews from 10 informants who had placed their family member while taking part in the focus groups. The purpose of the study was to explore what the transition was like for family caregivers, what they experienced when interacting with the staff of the facility once the care recipient was

placed, and how caregiving at home was different from caregiving in a long term care facility. The focus group data provided direction for the interviews, and was later analyzed with the caregiver staff relationship interview data Duncan indicates that interviews were analyzed using a "modified" grounded theory approach, as analysis did not occur as she moved in and out of the field.

Throughout the entire transition, Duncan found the themes "family" and "surviving" as highly relevant. In making the decision to place a family member in a long term care facility five themes were identified: the event, the health care system, the caregiver-care receiver relationship, support, and options and availability. An "event" did not relate to a single event but rather to a "turning point" in decision making that was influenced by caregiver exhaustion and care recipient disease progression. Turning points involved issues of safety, dealing with incontinence, and Alzheimer's disease progression. Most often caregivers described negative experiences and perceptions of the health care system involving themes of misdiagnosis, medication mismanagement, indifference, and staff's limited knowledge about Alzheimer's disease. These experiences in turn prolonged the caregivers' decision to place and influenced their ability to develop trust in the formal care facility. Influencing the caregiver care-recipient relationship was their previous relationship, the known wishes of the care recipient, and the care recipient's knowledge of previous caregiving experiences. Support was drawn from three sources: informal, formal, and self. Placement options and availability became significant over time and included aspects of pre-planning, beliefs and values, and realities, that influenced the decision.

In making the placement transition Duncan (1992) found that caregivers were adjusting to not caregiving at home as well as to the new environment. A paradox existed simultaneously of "trying to hold on while letting go". Shifts were noted by caregivers in three areas: control, involvement, and personal reorganization. Personal consequences of the move related to feelings, responsibilities for self, other residents, and role shifts.

Duncan (1992) found that development of relationships with the formal care staff was an important aspect of the placement transition. A key change in this placement transition was that the caregiver care recipient relationship now included the facility staff. In this process themes of caregiver-staff relationships, factors influencing the nature of this relationship, and caregiver evaluation of quality of care, were identified by family caregivers. Caregivers mentioned aides more positively than nursing staff as they were most often seen to be providing bedside care, and knew the care recipient's care routine. Duncan suggests that caregivers identified with aides because they most directly took over the caregiving duties they themselves had done. Factors that affected the nature of the caregiver staff relationship were monitoring, trust, staff behaviors, and family behaviors. Quality care was an expectation of the caregiver and was equated with treating the care recipient with respect in addition to adequately meeting care needs. Duncan suggests this may be a source of misunderstanding as facilities often define quality of care as the smooth running of the organization which differs from caregivers' perceptions.

In summary, several grounded theory studies looked at caregiving for a person with Alzheimer's disease throughout the course of caregiving; beginning when the caregiver

first realizes something is wrong and ending when care is relinquished to an institution. Other studies (Willoughby & Keating, 1991; Duncan, 1992), found that caregiving did not end with institutionalization but continued. Similar findings were identified in several of the quantitative research studies reviewed. Nevertheless little detailed information is available about the specific nature of the transitional process experienced by caregivers when the care recipient moves from in home to a long term care facility.

CHAPTER III: METHOD

In this chapter the method used in conducting the research study will be explained. Initially the guiding assumptions employed in the approach taken by the researcher will be clarified. Subsequently the procedures for sampling, data collection, and data analysis are explained. To conclude the rigor of the study is discussed in relation to the criteria of trustworthiness identified by Lincoln and Guba (1985) including: truth value, applicability, consistency, and neutrality.

Approach

In order to understand the process a family caregiver of a person with Alzheimer's disease experiences in making the transition from caregiving in the community to caregiving in a long term care facility it is necessary to gain access to the caregivers' viewpoint. The goal of a grounded theory approach " is to build theory that is faithful to and illuminates the area under study" (Strauss & Corbin, 1990, p.24). A qualitative, grounded theory approach was selected as appropriate to provide access to the caregivers' perspective and identify the process they experienced. Ethical approval for the study was received from the Ethical Review Board of the University of Alberta, Faculty of Nursing.

Sample

Inclusion Criteria

To be included in this study participants were sought who lived in the Edmonton area, spoke English clearly and considered themselves the main caregiver of a person with Alzheimer's disease. The care recipient had to have entered a long term care facility on a permanent basis within the last year.

Recruitment

Several strategies were undertaken to invite participants to take part in the study. Advertisements were placed in newsletters, newspapers, and bulletin boards inviting interested persons to contact the researcher. To ensure greater exposure, advertisements were placed in several forums, increasing the likelihood of being seen by family caregivers. An advertisement was placed in the Edmonton Examiner, a weekly newsletter delivered to all households city wide for two consecutive weeks; in the Sherwood Park News a weekly newsletter, delivered to the Sherwood Park area, and in the Alzheimer's Society Newsletter, delivered quarterly to subscribers in the region. "News for Seniors", which is a newsletter produced monthly by the Edmonton's Society for Retired and Semi Retired also carried advertisements.

Advertising posters (see Appendix A) were placed in several major long term care facilities throughout the Edmonton region. Permission to advertise in these facilities was granted by Capital Health Authority, on the condition that the researcher first contact the administrator of the facility, to make appropriate arrangements. All the administrators within Capital Health Authority's Long Term Care sector were informed of the study through a memo. The researcher contacted or met with a designated person, appointed by the administrator of the facility to explain the study and request permission to display the poster and recruit through the facility. In several cases permission was received directly. In four facilities' permission to place the bulletin had to be sought from the facilities' Family and Resident Council. In these cases the researcher contacted the staff representative and requested that the

research study be placed on the agenda. The researcher then presented a brief overview of the study to the council, explaining the aims of the study, and what would be required of participants, with a request to place the advertisement in the facility. The researcher attended and presented at Grandview, Lynwood, Dickensfield, and the Mewburn Veteran Center Long Term Care Facilities. In all cases the request was granted and the researcher agreed to relay a summary of the study findings to these facilities.

In addition, the Good Samaritan Society, a private organization which runs several local long term care facilities, was contacted and permission was received to place the posters within Good Samaritan Auxiliary Hospital, Good Samaritan Mount Pleasant Care Center, and Wedman Village Home, a new assisted living facility designed for persons with Alzheimer's disease. In several facilities personnel made a point of showing the poster to potential family caregivers who they thought might be interested and who met the criteria. From this more direct approach two caregivers came forward, while seven responded to the poster displayed in the facility where their relative was housed. Several mentioned that they also saw the advertisement in a newsletter. This seemed to add to the study's legitimacy. One subject came forward after an acquaintance of the researcher delivered a poster to his neighbor. After four months, when the tenth participant had been interviewed, thank you letters were sent to all the administrators of facilities who assisted with recruitment.

When volunteers contacted the researcher they were called by telephone to determine whether they met the inclusion criteria for the study. Those who met the criteria were invited to take part in the study, and if they agreed, a time and location

was determined for the first interview. Those who did not meet the criteria were thanked for their interest. Despite the screening process, during the first interview with one caregiver it became apparent that the diagnosis of Alzheimer's disease was unclear. In this case the researcher continued the interview, and upon return for the second interview the caregiver could clarify only that the care recipient had dementia.

Data Collection

A full explanation of the study was again given at the beginning of the first interview and questions and concerns addressed. In accordance with ethical guidelines the consent for participation was explained and signed by the caregiver, and a copy was left with them.

Participants were invited to choose a location for the interview that was free from distractions and other persons. Eight of the participants requested that the interview be held in their home; two agreed to be interviewed at the University for convenience. Interviews took place between April 1997 and July 1997, the second interview with the caregiver took place 1-8 weeks after the first. Interviews were tape recorded and transcibed verbatim. The tape recordings for two interviews were lost due to mechanical failure. Notes of the interview content were made during the interview in one case and immediately following the interview in the second case.

Each interview was one to two hours in length. The researcher was aware that the interview process may be fatiguing to participants, and prepared if necessary, to end the interview and resume at a later time. It was anticipated that talking about the institutional placement of a relative could be highly emotional for some caregivers. If

necessary the researcher was prepared to provide a referral to an appropriate health professional.

In total 19 interviews took place; two interviews with each of nine participants, and one interview one participant. During the initial interview the questions relating to the transition surrounding the placement process were unstructured, broad, and general in nature. This approach was used as the researcher was learning about the topic and wished to encourage caregivers to "tell their story" (Morse & Field, 1995). Examples of questions that were used to initiate conversation are listed in Appendix C. Several basic demographic questions (see Appendix C) were also asked to increase the researcher's understanding of the caregiver's situation. Prior to interviewing informants a pilot interview was performed with a colleague to increase the researcher's comfort level with the interview process. In turn the researcher took on the role of participant and was asked to answer the interview questions in the manner she expected participants to respond. By doing so the researcher had a better understanding of the questions and how it felt to be asked these questions. Also by providing expected answers, researcher bias was further examined.

Nine participants took part in a second interview which occurred between 1- 8 weeks following the first. The researcher was unable to reach one informant, despite repeated attempts, for the second interview. At the time of the second interview the researcher explored new issues and clarified themes arising from the first interview and beginning data analysis. Examples of the types of questions used are in Appendix C, however, the questions varied depending on the course of the interview and the first interaction with that participant.

Data Analysis

Once the initial interview was completed, the researcher listened to the audio tape and wrote field notes reviewing and recording comments relating to the context of the interview. This not only allowed the researcher an opportunity to become more familiar with the data, but to also document the context of the interview and aspects that could not be captured on tape. The audio tapes were then transcribed verbatim. Once the material was transcribed and returned to the researcher, the researcher reviewed the written material with the audio tapes for accuracy. Also at this time, material that could possibly identify the caregiver or care receiver was removed from the transcripts. By again reviewing the tapes with the audio material, increased familiarity was achieved, and any additional information recalled from the interview was documented in fieldnotes.

For ease in handling this volume of data, the computer software program NUD*ist 3.0 was used. Use of the program facilitated coding, sorting, retrieving, and creating memos about the data. In addition, this program has index searching and matrix building capabilities that aid in theory development (Miles & Weitzman, 1994).

Corbin (1986) explains that the major task in data analysis is "to code the data into categories then define, develop and integrate them" (p. 94). To begin this process, each paragraph was examined to identify the basic words and key categories. The intent of the researcher was to build and add density to these categories, examining properties, dimensions and relevant conditions. Once primary categories and their dimensions were identified emphases was given to analysis of the linkages between and among the categories.

Data collection and analysis proceed simultaneously in grounded theory (Strauss & Corbin, 1990). As data were collected, preliminary review and data analysis was completed and emerging ideas employed in guiding subsequent data collection. There was variation in the background and caregiving context of the participating caregivers. For example the sample included caregivers who placed their relative in a crisis and those for whom placement was a planned event. Events surrounding placement varied, in several cases the death of the main caregiver had recently occurred, or increased difficulty was experienced in managing and caring for the care recipient due to declining health on the part of care recipient and or caregiver. One care recipient was transferred from a hospital whereas others were placed from the home setting. Also the long term care facility where the care recipients were placed varied widely, and were scattered throughout the city. These facilities included locked special care units for the cognitively impaired, general units, in addition to two newly opened care facilities specifically designed for persons with Alzheimer's disease, one a larger facility, another an assisted living setting housing a maximum of eight persons. In view of this variation, the opportunity for two interviews with 9 participants and the ability of caregivers to articulate their perspective, 10 participants was found to be adequate for data saturation.

Identification of the core category, often a process, usually appears late in the data analysis, and is the central theme connecting all other categories (Corbin, 1986). The core process identified in this study was "redefining one's caregiving role" when care recipient's needs outweigh caregivers abilities, as a result of factors such as care recipient decline, and/ or limited caregiver ability or resources.

Once analysis has identified a core category and sub categories, a key step is the verification of findings with the same participants (Corbin 1986). Morse and Field (1995) state that theoretical verification is an important step in the research process. Once analysis was near completion and it was felt that saturation was achieved, the researcher carefully reviewed each participant's transcripts to verify that in fact the stages of the process could be identified. The researcher was satisfied that all had met this criteria, although, not all caregivers were in the final stage at the end of the study.

Rigor

Lincoln and Guba (1985) state four criteria must be addressed in determining whether a study is trustworthy. The four criteria include: truth value, applicability, consistency, and neutrality, and will be addressed in relation to the present study.

Truth Value

Sandelowski (1986) states that, in a qualitative study, the truth value is evident in findings that portray human phenomena and experiences as they are perceived by the subject. The presentation is credible when other people, going through a similar experience, can recognize their own situations in the information (Morse & Field, 1995). Several strategies were used in this study to enhance truth value. For example during the interviews an audio tape recording was made to document the entire conversation verbatim. Careful placement of the microphone near the participant during the interview was arranged to capture softer, lower voices. The audio tapes were transcribed verbatim including pauses and other sounds (i.e. a sob), and rechecked by the researcher to ensure accuracy. Fieldnotes were made immediately after the interview to supplement audio material. Fieldnotes provided information on

the context of the interview, as well as descriptive detail, adding to the richness of the data.

Attempts were made from the beginning to achieve rapport and gain the participant's trust, as well as enhance their comfort and ability to speak openly and honestly with the researcher. The setting and timing of the interview was the informant's choice to enhance comfort level and feeling of ease. Most participants were involved in several interviews, and in all cases the researcher felt that participants felt comfortable with the researcher to speak openly. Participants were reassured that they may only share information they felt comfortable sharing, and as the direction of conversation was led by the participants, a non threatening environment was achieved. In fact after the interview many thanked the researcher for listening to their "story" mentioning they appreciated having someone they could talk to who was aware of what they had to go through. In addition the second interview offered an opportunity to clarify and verify prior information with the informant, again ensuring accuracy.

Applicability

Applicability or transferability relates to whether the findings can be applied to other groups, situations, or settings and the degree to which others can identify with the findings (Lincoln & Guba, 1985; Morse & Field, 1995). In this study variations within the group of caregivers were sought in order to obtain a clearer, more comprehensive picture of the phenomena being studied (Sandelowski, 1986). A great deal of variation among participants occurred in this study despite the common

element of all having placed a family member with Alzheimer's disease in long term care within the past year.

In an attempt to determine and achieve the "fit" of the developing theory (Glaser & Strauss, 1967), where possible terms used by participants were used to explain the process, as well as direct quotes from transcript material. In addition, terminology was specifically selected that could address and capture the variation within a particular phase or stage and yet be easily understood.

Consistency

Consistency refers to whether the findings would be consistent if replicated with similar subjects in the same situation. Lincoln and Guba (1985) argue that to achieve consistency in the naturalistic paradigm, dependability must be considered in order to account for factors relating to instability of phenomena or design induced change. To address this, and enhance rigor (Rodgers & Cowles, 1993) the researcher maintained an audit trail. Clear documentation was maintained in regards to all decisions made as the study unfolded. Four types of documentation were included: contextual information (fieldnotes), methodological memos, analytical or theoretical memos, and personal reflections or memos. Memos were maintained as part of the data base permitting access to and analysis of memos, fieldnotes and data using the NUD*ist software program. In addition a binder was available for notations when the researcher did not have access to the computer. By consistently documenting thoughts and decisions during the study the researcher as well as advisor could then follow its progress with clear understanding.

Neutrality

Neutrality relates to freedom from bias in the research procedure and results. In qualitative research this is achieved by prolonged contact with the informant and the researcher's ability to identify bias arising during the study (Morse and Field, 1995). As mentioned, two interviews were conducted with the majority of the informants over a period of several months. The researcher, a former home care nurse, found it necessary to examine and monitor possible sources of bias arising within herself. However the researcher felt able to maintain a neutral attitude throughout, even for example when many of the participants commented on inadequacies within the health care and Home Care system, at times venting negative feelings such as anger and distrust. Also, from the beginning, to avoid being affiliated with any agency, the researcher did not volunteer previous work history information, and was not pressed to disclose this information by participants. The researcher, in fact was not caught by surprise by these statements having worked within the system and having encountered these concerns in the past. Maintaining a neutral attitude was made easier as the researcher had not worked in that setting for several years, so felt distanced from the situation, yet with a degree of familiarity. By recruiting informants through news media and posters rather than exclusively from a particular long term care or community agency, the researcher was not seen as connected to "the establishment". In this way participants could speak candidly about their situation and experience, both positive or negative, without fear of reprisal. Also the researcher assured participants that responses were not being used to evaluate placement or agency services.

CHAPTER IV: FINDINGS

The Process of Redefining One's Caregiving Role

The original purpose of this study was to uncover the transition experienced by family caregivers' of persons with Alzheimer's Disease from caregiving in the community to caregiving when the care recipient has entered a long term care facility. Other areas explored included the events and experiences leading to the decision to place their relative, factors influencing this transition, and changes in the caregivers' caregiving after the care recipient was placed in a long term care facility. In this chapter the findings derived from this study will be presented beginning with a description of the characteristics of the participants, and followed by a general overview of the process uncovered. More detailed presentation of the findings beginning with an illustrative case situation follow.

Study Participants

Of the ten informants who volunteered to be interviewed for this study two were husbands and eight were daughters (see Appendix D). Four caregivers lived with the care recipient before placement, while six lived apart. Three of the ten admissions to a nursing home were considered an emergency, one because of the care recipient's fall and resulting difficulties, one as a result of the caregiver requiring sudden hospitalization, and one due to the sudden death of the main caregiver. Four of the ten care recipients had recently lost a spouse, and of the widowed two were subsequently placed. All the caregiving daughters were in their middle years, whereas the two spouses were ages 73 and 82 years. Employment status ranged from

full time, to part time and retired. Four of the caregiving daughters were married, and three were single and never married, and one caregiver's marital status was unknown. Time spent as the main caregiver varied from several months to nine years at the time of the first interview.

Redefining One's Caregiving Role: An Overview of the Process

From the information provided by the participants, four phases were identified in the transition from caregiving in the community to caregiving for someone in a long term care facility (see Figure 1.) These phases were: "realizing", "preparing", "finding the way", and "carrying on with ongoing change". In referring to the figure the process begins with the caregiver "realizing" that care recipients' needs outweigh the caregiver's abilities and resources. Over time, with the advancement of the disease process and changes in the care recipient needs, demands on the caregiver increase. During this time, caregivers themselves also change and their personal strength and abilities vary. While trying to meet the needs of the care recipient and find suitable solutions for caregiving dilemmas, caregivers are "facing limitations" which can arise from a variety of sources such as the care recipient, the health care system, family and community, and even the caregiver themselves. As the caregiver encounters further challenges and seek possible solutions, the repertoire of limitations and challenges faced in the past serves as a reference point.

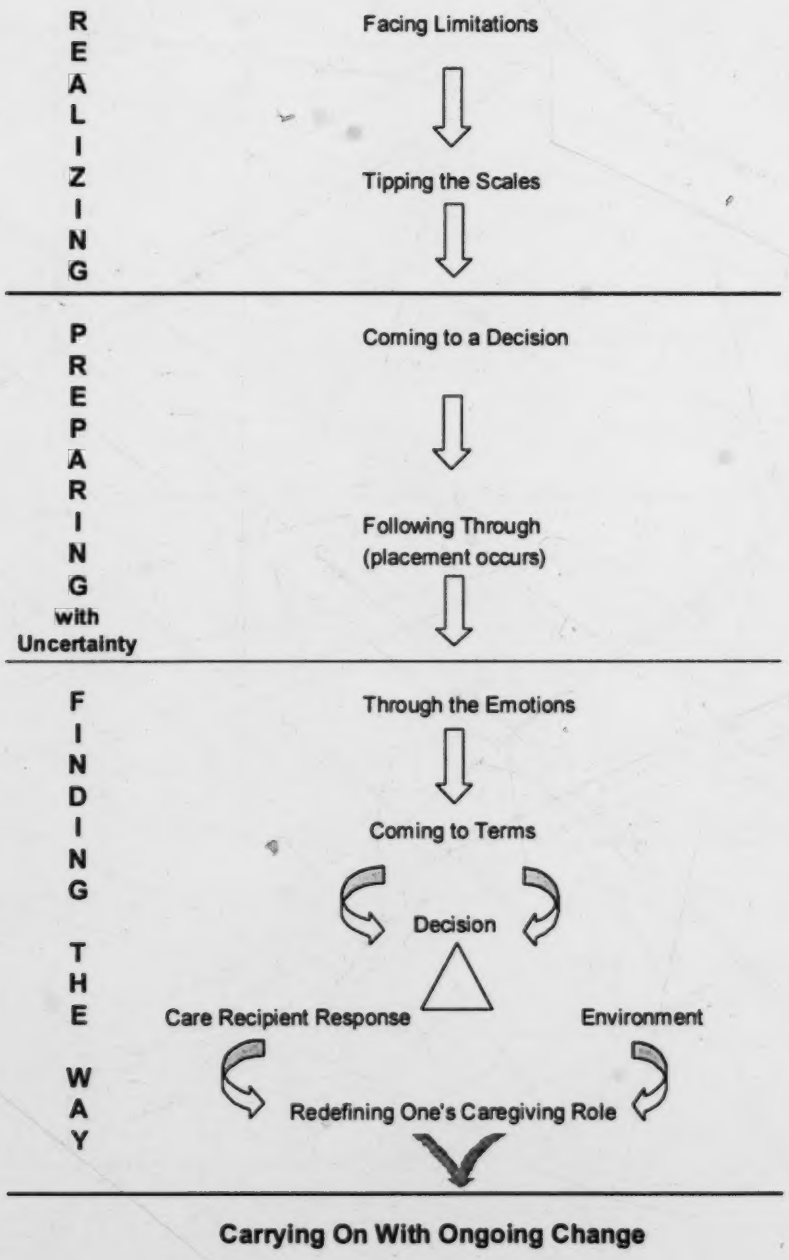
Then a crisis or series of trigger events occurs which has a profound effect on the caregiver, and begins "tipping the scales". The degree of effect may depend on the number of outsiders involved, and the safety risk to the care recipient. During and after the trigger event(s) the caregivers begin to realize that the care recipient's needs

outweigh their caregiving ability in the present home environment and concerns for care recipient safety override concerns for autonomy and independence.

The caregiver then moves to a phase of "preparing with uncertainty" where the caregiver begins "coming to a decision" as preparations are made that move towards making a decision. Ultimately the caregiver enters the stage of "following through" when permanent placement in a long term care facility takes place. This is a time of uncertainty for caregivers, as they are uncertain whether this is an appropriate step to take, and whether other options should be examined further. As well, uncertainty surrounds the timing of the event, as there is little warning about when the move will occur, and exactly where the care recipient will be placed. Throughout the entire process the goal of the caregiver is to make the best decision possible and to "do the right thing".

Once the care recipient is placed in a long term care facility, the next phase encountered by the caregiver is "finding the way". This is a period of adjustment and change. Many of the caregivers experienced a period of intense emotions, likened to mourning and grief. For some relief is also present, however for others, particularly those extremely close to the care recipient, recognition of the benefits may not occur until the strong emotional response lessens and they have begun to "come to terms" with the situation. Caregivers had to "come to terms" with several aspects including the decision, the environment, and the care recipient's response. Each aspect is interrelated and greatly influences the caregiver's emotional level of comfort. For example if the care recipient declines after placement the caregiver may question the decision and the care environment in which the care recipient is housed.

Figure 1. A diagram of the transition process entitled redefining one's caregiving role.



As caregivers begin "finding the way" and "coming to terms" with the placement decision, they are more able to clearly "redefine their caregiving role". Aspects of redefining one's role can be seen in the initial "realizing" phase. However as the caregiver moves through "finding the way", greater clarity is achieved and the caregiver begins to redetermine their level of involvement and caregiving focus within the long term care setting. Often a shift in focus occurs from providing physical care to concern for the emotional care of the care recipient. Also, as this experience serves as a marker of the care recipient's decline, the caregiver also concentrates on maintaining a connection with the care recipient. The caregiver's activities involve attempts to remain connected and spiritually close to the care recipient. In addition, as caregiving duties are taken over by the facility staff, caregivers find they have more time and can refocus attention upon themselves, which in turn fortifies their strength and ability to continue in the caregiving role.

As caregivers begin "coming to terms", and "redefining their caregiving role" they enter the last phase identified in this study, titled "carrying on with ongoing change". In their newly redefined role they begin to establish routines, and a certain level of comfort is achieved. Caregivers feel they have adjusted somewhat to the move and although the initial intensity of emotion and grief has lessened, it remains to a certain degree as the caregiver continues to face changes related to the care recipient's disease state. The case situation which follows was constructed from the experience of several women in the study to illustrate how an individual caregiver moved through the phases to the point of "carrying on with ongoing change".

An Illustrative Case

BD a middle aged woman, works full time, and lives with her husband and two teenage children. Her mother, who is in her eighties, was diagnosed with Alzheimer's Disease four years ago and had been managing with the help of her husband of 55 years, and occasional help from home care and BD for outings and groceries. Suddenly two months ago BD's father passed away, leaving BD to care for her mother. She also began to realize the full extent of her mother's difficulties. She enlisted additional help from home care but found that her mother required someone present more than several hours per day, as she could no longer cook, remember to take her pills or follow simple instructions. BD telephoned her mother often but even then arrived one day to find her mother with a large open gash on her forehead received from a fall earlier that day. BD's mother refused to go out and did not like to answer the door, making it difficult for the cleaning lady to gain entry. BD, feeling she had run out of options, placed her mother's name on the nursing home list. In addition to convincing her brother who lived out of town that the decision was necessary, BD was given a list of nursing homes to visit so she could make her preference known. BD tried to prepare her mother for the move but soon found that her mother did not remember being told, and she could not tell her when and where it would happen anyway. For the first while, after her mother was admitted, BD felt extremely sad, cried often, and had difficulty sleeping. She was concerned about her mother's recent weight loss and found her less talkative and more confused. BD spoke to the head nurse about her concerns and asked if anything could be done. She began bringing in her mother's favorite foods, and pictures and momentoes she knew

her mother would remember. BD was very pleased when her mother started gaining back her weight, and greeted her cheerily when she arrived on the unit. Now BD visits twice per week often taking her mother to the cafeteria to have a snack of pie and coffee, a ritual they shared when they visited at each other's homes over the years.

Realizing

Alzheimer's Disease is disease of progressive cognitive decline. Individual variation may occur regarding the symptoms exhibited, behavioral changes and disease course.

Caregivers strive to meet the needs of the care recipient. When faced with a slow progression, caregivers can provide care with the assurance that the care will be well received by the care recipient. In some cases it is difficult to predict the care recipient's response and caregivers may be left " scrambling" trying to fill in the gaps. To maintain a balance in caregiving, the care recipient's needs must not outweigh the caregiver's resources and abilities. In this study, the number of years caregivers had been providing care varied. The longest amount of time was nine years, the least only a few months. When changes occur in the care recipient the caregiver identifies a problem or area requiring attention and works toward a solution. "Realizing" can be an acknowledgment of the need for minor or major change depending on the degree of change in the care recipient. For example, when one caregiver realized she could no longer manage both her own and her father's laundry she convinced her father to take his laundry to a laundromat. Alternatively,

realizations that result in placing a family member in long term care can have ramifications that impact every aspect of one's life.

Facing Limitations

When faced with caregiving challenges, caregivers try a find appropriate solutions. Options and alternatives are generated in an effort to solve the problem at hand and keep the care recipient home safely. As the caregivers investigate these options and alternatives with the care recipient, other family members, and even with the health care system, they begin to face limitations. While dealing with these areas they gather experience and knowledge of what was done in the past, what is and is not available, and what was successful or unsuccessful. The limitations faced can come from several areas: the care recipient, the health care system, and in some cases the family, or community .

The Care Recipient

When caregivers attempted to make changes or add services to assist with the care of the care recipient, all care recipients in this study met these changes with a degree of rejection and anxiety. This is turn caused the caregiver a great deal of frustration. In some instances the caregiver went to great lengths to provide appropriate services which were refused, sending the caregiver "back to the drawing board" to find a new solution. However, the caregiver did so with the knowledge and experience of this recent incident. Some hesitated to propose a new solution, as they recall the previous reception received. The following statements highlight one caregiver's situation:

> *We were at a state where not only couldn't we help her, she wouldn't let anyone else help her. You couldn't make any arrangements.*

I was in the position that I could not go back to that group (Meals on Wheels) and ask again because there are volunteers that are delivering the food to begin with so they don't have any of the knowledge of her condition. In addition they don't have the skills to deal with that. Most of the people they are delivering to are shut-ins who are very grateful for them coming to their door and here my mother is turning them away.

Another caregiver describes her frustration in suggesting ideas to her mother and always being met with resistance.

...as soon as you suggest it, it isn't a possibility. If somebody else suggests it. So then we have to do this complicated getting other people to suggest. And then it is a possibility. Like cleaning up the house. She didn't want us to do that. When we came we were just supposed to visit. That was all we were supposed to do... 'what are you doing that for?' she'd say 'come and sit'. So we would always have to work behind her back. 'Just try some home care'. 'No, no I'm fine'.

Once services were arranged MG describes the difficulties related to her father's not allowing services into his suite.

Then I started getting more help as he deteriorated- getting more help from home care coming in... Home care won't go into the suite unless you let them into the suite. But dad couldn't remember. Half the time he didn't have a key anyway. Again they bent over backwards and they would go all the way from the office down there-open the door for the Home Care and let Home Care go in on their own. Again, they wouldn't let Home Care in. Absolutely not. They could be charged. I made my brother draft up a letter saying we will never ever hold you responsible for anything that is missing in the suite. We will never ever do this, or this, we will never blame you. You guys are doing us a favor, please. I mean the phone calls, my boss was so mad, I was very close to being fired because I was spending so much time on the phone.

One caregiver explains her frustration with her mother's difficulty with decisions.

And then a space did come up so we took her to see it and she would say "Yes" and then she would say "No" and she would be very keen and then she would be very indignant that we would be moving her out of her house and 'put me on the list' and 'take me off the list' and

it was very frustrating to us. I wanted to do the best thing. I wanted to be supportive but when is she in her right mind and when is she not in her right mind? Which of these requests is the true one? Yeah, it was very difficult... We got her on the lodge list which is a difficult thing to do because she had to sign something and 'what is she signing?' and 'what are we up to?'

As one caregiver's mother became more paranoid it became even more difficult to provide care.

We had involved a home care nurse on an infrequent basis. My mother refused to accept any help but we convinced her to do it for my father because he had a heart pacer and was not really feeling well. He was 87 years old. So the nurse was coming by and sort of monitoring the situation. After my father passed away they provided home care overnight for a few nights and then tried to provide it during the day and in the evening. However, it turned out that my Mother got even more paranoid. She was refusing to accept the care.

The Health Care System

Limitations may also be experienced in relation to the health care system which may provide services or suggest options for care. Services, are meant to support the caregiver. However as the care recipient's needs increased and requests for service were made, many caregivers became painfully aware of the limitations in the "system". Limitations related to service limitations, financial limitations, and limitations in ability to deal with persons with Alzheimer's Disease within the "system" itself.

Yeah because of all the health care cutbacks with Klein and that, everything has been cutback. Even when we wanted to get extra help, when Dad was in the lodge, it got to the point where 'Your father is getting x amount of hours we can't help him anymore' type thing and it was like I was already stressed to the max knowing I couldn't keep running my household and his household and taking care of him, you know.

The whole business seems totally fragmented.

I would say that the early part of 1996 was the time that she needed the most care and I did ask for Home Care to come in to give me a break-to let me get out for an hour or two during the day. I had Home Care for about 10 hours for the week. It was split-say four hours in Tuesday and two hours on Wednesday and two hours on Friday-something like that. It was all right to give me a break like that but I didn't feel that was sufficient home care for M. They were just probably a sitter. They came in and sat with her and probably read to her. That was the extent of the home care. ... it really wasn't sufficient to be of any help to me.

Personal Limitations

Caregivers also face personal limitations in relation to their situation and their ability to carry out their role as caregiver. In the example below "personal limitations" are mentioned as the caregiver is not feeling up to the task due to limited experience in caregiving and limited knowledge of the services and resources in the community.

Well if there would have been someone that I could call. Like I should have been able to call it seems to me her health care worker who was in charge of her case and say to her 'Well mom has fallen. Now she needs something'. Instead of them saying 'You have to do more'. They always said 'Well, you do more'. They never said it quite that frankly but essentially that was what they meant. ' We can't do anymore. We are at our limit. The family has to do more'. Well! and not even tell us what more was. So there was no one to call. I mean there was her doctor, but so all of her people were helpful in as far as- in this very limited way. I was in charge. I didn't like to be in charge. I didn't feel like I had a broad enough view to be in charge of what was available and how to fit it all in and how even to find out.

Other caregivers face limitations in their ability to provide care due to other obligations such as work and family. In fact several caregivers in this study were also caregivers to other family members. One caregiver cared for a daughter with mental

health concerns, another cared for a mentally handicapped sibling and in feeling overwhelmed, states:

> *Each was sick and each had to he fed and each had- you know- and if they were in pain you had to deal with that. You couldn't put that off so that meant that any needs I had had to be put on the back burner and forgotten about.*

Due to the rigorous demands of caregiving, some caregivers find they are not physically up to meeting the challenge. Personal health status may change while providing care, such as in one caregiver's diagnosis of cancer. Another caregiver with a heart condition, found his wife's night wanderings extremely difficult. Physically he became worn out, and realized he did not have the endurance needed to continue in this manner so when placement was suggested, he agreed. Carrying an extreme caregiving burden, and ignoring her own health, one caregiver had to be rushed to the hospital. As a result her mother entered a long term care facility on an emergency basis.

> *From the time I took over the situation I was basically on the verge of being a patient. From the time I took on all of that because I didn't have enough help. I was on the drain right from then on. I was functioning under par because I was overloaded. You can overload a person and they can probably go on emergency rations over and over for a week like that but to be on emergency rations over and over for an extended period. Their system is run down by the end of the week they are run down. Then they are working on sheer nervous energy or what you call it and that's where you can run into- like somebody told me adrenal exhaustion. You have overworked it and the body is ready to lay down and say no-no I am not going any further-this it is.*

Family and Community

Caregivers may face limitations when calling upon family and community support. Many of the caregivers described limitations within the family system to provide care

to the care recipient. Caregivers realize who they can and cannot call upon for assistance. In some instances the family member may not be available due to distance, infirmity, or their personal difficulty dealing with the care recipient's situation. Due to the cognitive impairment experienced by the care recipient, caregivers maybe reluctant to call upon others, particularly those with little understanding of the care recipient's situation.

> *It would have been easier if I would have had my brother at home or girlfriend that I have got or cousin. If they had been there-they would have said I will spend today with your dad you go to your mom (in hospital). There was nobody else to do it.*

An example of encountering limitations in the community occurred in one caregiver's case as she describes contacting nearby businesses and requesting that her father not be served alcohol. Even after explaining her concerns and her father's situation, she was told that there was nothing they could do about this unless he is bothering them or stealing. She then describes "harassing them" and as a result they approached her father on his last visit and said he could no longer be served due to his medical condition.

Due to the complexity of the situation, the caregiver may encounter several interrelated limitations simultaneously and/or continuously. For example one caregiver who worked full time found coordinating services difficult due to the amount of time involved in making arrangements and it was suggested that she take an early retirement.

> *I tried my best to try and trade off time. If I was late then I would stay late or I would give up my coffee or lunch breaks... I was trading off time which also created some problems.*

Another describes feeling unsupported by her caregiver support group:

> *Here I was in charge but what was I supposed to be doing. I wanted to do it well but I didn't know what it was. So many people in that (support) group were putting their parent usually their mother in a nursing home. They all thought I should too. They all thought I was at fault for not doing that. One of mom's neighbors said to me 'this is a case of elder abuse'.*

Tipping the Scales

In the stage of "tipping the scales" the reality of the caregiving and care recipient's situation becomes more apparent for the caregivers and they begin to recognize that the care recipient's care needs are beyond their abilities. For all the caregivers in the study a significant event or series of trigger events occurred just prior to the placement decision. These events are the beginning of a turning point when the caregiver identifies real and/or imagined concerns and seriously considers placement as an option. Real behavioral concerns are the actual behaviors the care recipient has displayed, such as wandering. Real concerns are magnified when an imagined concern, or "what if" is added. An example mentioned by many of the caregivers was the coming cold weather and "what if" the care recipient wandered out in extreme weather. In many instances imagined concerns related to safety issues. This can be seen in the following statement:

> *Basically at that point it was either get him into care or it was going to kill my mother. She had lost an awful lot of weight, she wasn't sleeping and at that point too-he didn't sleep much during the night...*

In the above situation, adding to the difficulties, several incidents of wandering occurred. The last incident which was most alarming is described below.

Then there was the really frightening, well ...it was and it happened about a week before he went into care and I think it was one of the reasons we got him admitted so quickly. He had gone to the Bank and he got turned around and ended up at the traffic circle by the mall and he was walking on the road around the traffic circle. The cars whizzing around and they were honking at him but they weren't stopping. Two ladies stopped. That wasn't the way they usually go. They did that day. The one lady who was the passenger, who had a mother-in-law with Alzheimer's. She saw dad out there walking around and she knew there was a problem. She had her friend stop. They were the only car that stopped. She got him off the road and onto the grass in the middle of the circle and talked to him and asked him where he was going. He said he was going to the bank. They said well can we give you a lift. This would have been March. It wasn't a bad day but it wasn't really warm and she said you're cold. He was just shaking. Probably a lot was nerves and because he was upset and confused. I talked to both of them afterwards and they let him off at the bank and he wouldn't go in. He said well I've already been in. So then he started home, but she decided that she had better follow him. Her friend had a cellphone and stayed at the bank and called 911 to get help. She followed dad all the way home. He let her walk with him two blocks then got quite agitated and so she let him go ahead but the light at the avenue was red and she didn't know if he was going to stop or not. He stopped and she didn't follow him right to the door but could see that he went down the back alley and she could see the gate where he went in. She figured he was home. By that time a cop finally showed up. He went and talked to dad. Mom wasn't home. It turned out that she was on her way home. He tried to talk to dad and dad wouldn't answer the door. He went to the next door neighbor's and explained. Luckily it was the neighbors that knew what was going on and he explained to them what had happened. They phoned me and I was at work and I said that mom would be home within five or ten minutes. She was and he told her what had happened and he talked to father. That was very scary. At that point mom realized that he was beyond her control.

An example of a series of events began for one caregiver when her mother fell and fractured her shoulder. She underwent surgery, and a few days later her father, the main caregiver, passed away suddenly. The care recipient was transferred from the rehabilitation hospital to a long term care facility.

In some cases a crisis or series of events occur that primarily involve the caregiver and thus impact the care recipient. For example when one spouse died suddenly, one daughter was left to care for her mother. Due to the extent of her mother's care needs, she was unable to care for her mother on a full time basis and her mother was admitted to long term care on an emergency basis two days after her father's funeral. One gentleman in his 80s, describes the following event, shortly after he was diagnosed with cancer, which led to his decision:

> *So I have cared for her at home for the last five years and didn't find it a chore because she was able to do things on her own and she had mobility... early 1996 she was losing mobility a bit and I bought this chair to wheel her from the bedroom to the bathroom and into the kitchen for meals but she didn't use the chair all the time because she was able to walk with my assistance throughout the house and it wasn't until April that we had been out to visit a friend in the nursing home... and she collapsed in the hallway so I had to have assistance from the staff to get her lifted up and help her out to the car.*

In cases where the care recipient does not live with the caregiver outsiders may be communicating their concerns. In this study several caregivers were alerted to events and behavioral concerns by lodge staff. In these instances continued housing of the care recipient within the lodge was considered in jeopardy. A caregiver related how when her father first moved to the lodge they requested she sign a waiver ensuring that family would move the care recipient when problems arose. She refused and instead signed a document stating she would work with the lodge to arrange the next step of care because she was afraid of having to take her father to her own home if nothing else was available.

> *...the lodge phones stating that they felt they no longer could keep him because they deemed him as too high risk for the lodge. He was leaving the lodge inadequately clothed last winter when it was very*

cold. He would just leave in his sports jacket, no hat, no coat, no mitts, no boots, to go to his lady friends.

Another caregiver describes how the lodge alerted her on several occasions of troubling behavior- often times finding a solution, until it began to worsen. The caregiver describes the situation in the following statement:

They(care recipient and his girlfriend, also with AD) are starting to get bad. The weather is getting colder. Because they were getting meals regularly Dad was starting to go over to the mall and then he would forget to come home. They would send staff over there and they don't have the staff to be sending over there. They were concerned. Dad would go without a hat or coat on. I said R (brother) I am just scared to death. I don't want dad to die and that lady that had died in the field. That just kept coming back at me. I don't want dad to die that way, I just don't...

Throughout the caregiving experience safety of the care recipient is a concern that has to be addressed by the caregiver and solutions put into place. One caregiver in the following example describes dealing with safety issues when her father lived alone in an apartment before moving to a lodge setting.

Dad's getting to the point where he needs more care than he is getting. He opened up a can of sardines. They smell bad enough anyway and he put them in the microwave in the tin and we found them three weeks later growing. I mean- scream! You would find his comb in the fridge and just things like that I knew that it was coming to the point that he needed more care. I did not feel safe. As a matter of fact I took it upon myself to take all the fuses out of the stove...I didn't want him cooking anymore. I didn't want him starting a fire.

Crises and the personal limitations experienced changed the caregiver's view of the caregiving situation. The first issue to be addressed in response to the crises is the issue of safety. The caregiver more thoroughly realizes the care recipient's vulnerabilities. In the past, when making decisions or monitoring the care recipient's behavior, independence and autonomy were strong considerations. As the care

recipient's behavior becomes more of a concern, particularly in light of a recent crisis, caregivers realize that the care recipient's safety outweighs their independence and autonomy.

Before the crisis began to build, a caregiver comments:

> *She was refusing to accept care. But still she wasn't doing anything that would be regarded as harmful to herself or others. She was not- she was doing illogical things- she was hiding everything and then she couldn't find it and then she would think someone had broken in and then she would hide things more. It became a vicious circle. But she didn't do anything like- we didn't notice her leaving things on the stove or doing things like that. She seemed not to get lost going to the local mall, that sort of thing.*

For her, the scales had not yet begun to tip. However as her mother became increasingly paranoid, refusing assistance, losing weight, and not taking her medications, both real and imagined safety concerns became paramount. Despite valiant efforts, the situation couldn't be resolved and the caregiver realized that her mother's safety was at risk.

> *...before she went in I didn't know that she might not have a memory lapse and start wandering around outside in the cold weather and freeze to death or try to go to the Mall and lose her way. I bought her a bracelet but she refused to wear it. With Alzheimer's on it, there was contacts and everything on it. We did try a variety of things but it didn't help..." "The worry I had at the last was actually physical. I was worried that she might get up in the night and fall down the stairwell or forget where she was and turn the wrong way and do something like that. I was starting to worry about her personal safety.*

In the following statement one can see a change in another caregiver's mindset, from one of encouraging and supporting the care recipient's independence to realizing that his safety may be at risk due to his cognitive decline.

> *He was riding a bike and they would say I don't think your father should ride a bike. 'What happens if he gets lost or gets killed or*

something?' Well then praise the Lord. That sounded rotten but, praise the Lord he dies. I would rather him die happy riding his bike in traffic doing something he wants or die dancing. They would say don't let him dance maybe he'll get a heart attack. Let him get a heart attack. I don't want to see Dad deteriorate. I hope I don't ever see him deteriorate. But I will have to cross that bridge as I come to it if he does. I am not going to stop him from living just to protect him but I have to now. It is like I just knew. I knew when I had to protect him and when I had to let him go.

Eventually she recognized that priority had to be given to his safety although she had not anticipated placement.

The thought of him hurting himself. I would rather have dad alive and maybe mad at me for putting him in too soon than to have him dead because we didn't show enough caution... I never really said to myself he is going to be in long term care at this point in time. I just wanted him to be independent as long as possible. I guess in that sense I was thinking about it somehow. But I never thought he would deteriorate the way he did.

When faced with limitations and a grave safety concern, caregivers are also faced with the realization that they may not be able to meet the care recipient's changing needs in the present situation. They come to the realization that the care recipient's needs are beyond what they can presently provide as caregiver. As described in the following statement after the crisis:

That was very scary. At that point Mom realized that he was beyond her control. Because even if she had been home he would have said to her I am going to the Bank and wouldn't have... and I could see that my father was difficult even for my sister and I to handle. We couldn't handle him. We couldn't be there 24 hours per day. He wouldn't accept any live in help... he had restricted his options.

One caregiver describes how she believes she missed a prime opportunity to assist her mother to move to a long term care setting because she did not realize the extent

of her mother's difficulties. She had ignored her mother's earlier request for assistance to move to a lodge:

> *I didn't realize at the time she was having trouble.* (Then when her father suddenly passed away) *it became clear by then that mom was not functioning as well. So I guess we had a window of opportunity there that she was still well enough that she would adjust to a move, but because it didn't happen the window closed and she became so she didn't want to leave her house, but she got worse.*

During the stage of "tipping the scales" the caregiver undergoes a realization that the of the care recipients needs outweigh their caregiving abilities and resources. This realization can occur as a result of a crisis event or a series of events. Once caregivers begin to realize their situation, they then look at their options and possible solutions, keeping in mind the limitations faced in the past. It is at this time they seriously consider placement as an option, and move into the next phase of "preparing with uncertainty".

Preparing with Uncertainty

As the caregiver enters into the phase of "preparing with uncertainty" they move towards the stage of "coming to a decision" followed by the last stage in this phase of "following through" with the decision, at which time placement occurs. Throughout the pre placement phase of preparing, a sense of uncertainty permeates. There is uncertainty about coming to the decision, whether the right decision was made and how the care recipients will adjust to their new environment. Once the decision is made the caregiver, and health care system are uncertain about when the placement will occur, and where it will occur.

Coming to a Decision

Formal preparations assume a new importance once the caregiver realizes that they can no longer care for the care recipient in the present situation, but resources and options are limited. In weighing options and trying out different strategies they form a sense of what works and does not work; what is available and what is unavailable. For some, consideration of the possibility of placement may occur much in advance of the actual date of occurrence. For example one caregiver stated she began thinking that long term care placement would eventually have to be considered when she first heard the diagnosis. Some caregivers "arrive" at the decision to place the care recipient, having traveled through months or years of caregiving. The caregiver may see placement in a long term care facility as the only available option. Eight of the ten caregivers in this study however did not arrive at this decision by themselves. For these caregivers, others played a key role in this decision by posing the suggestion of placement as an option that should be considered. The relationship of these persons to the caregiver varied, but all were considered knowledgeable about the care recipient/ caregiver situation. For some it was a close family member, or sibling, for others it was a health care worker, or lodge staff.

Preparations

Preparations for placing the care recipient in a long term care facility are both mental and physical in nature. Mental consideration of placement may occur at any time during caregiving. Ideas and views are formed on long term care early in life and will influence later decisions. As caregivers go through the phase of "preparing with uncertainty" they are beginning to prepare for placement of the care recipient.

Physical preparations involve the execution of mental preparations, including making the decision known, contacting the long term care system, and convincing others. As well, a great deal of practical day to day concerns need to be addressed. These include, for example preparing the care recipient's home for sale, or seeking a guardianship order.

Making the Decision Known

Caregivers do not work in isolation, but within a complex health care system, and family system. Because of this complexity, being heard is vital for success. For some caregivers who are already in the "system" all that may be required is a call to the key persons to convey their intent and relay their concerns. For others, the process is more involved and includes assessment forms and medical exams to be completed on the care recipient.

In this study several of the caregivers relate having to convince the health care personnel of the reasons that placement was needed. For example, one caregiver prepared herself for a second interview with the admission personnel, realizing she had not stated her case well enough the first time.

> *One time they had come to interview dad a year earlier than last year about the assisted living home and they said your father didn't seem that bad to be coping OK, so we won't bother. I was too scared to tell them how bad I was. This time I said listen I almost had a nervous breakdown. I said I do need help and I says the reason dad seems to be doing so good is because I am there. When I am there dad doesn't have any worries when they have questions. You take dad alone and he won't be able to tell you what the date is or anything.*

As they were preparing the documents to begin placement, another caregiver took her mother in to see the social worker

I am going to go up ... and see if the social worker's there so she could put a face to my name, you know a little more human aspect. I stopped by to see her and had a little chat with her and she needed some more documents so I got those and then a couple of weeks later I was going to drop the documents off and I had my mother with me...I had phoned to make sure she would be there and told her approximately what time I was going to go. So I took my mom up. Maybe that helped too. I mean she took one look at my mom and said how are you doing? It was like sit down before you fall over. How are you doing? and I said not well.

For some, the work continues after the health care personnel involved in initiating the process have been convinced. Some take up a vigil to ensure that the wheels that have been set in motion do not stall, and that they are being heard. In addition to being vigilant, some indicate that it is necessary to take action. As can be seen in the following statements:

I guess I was lucky in that respect because I know some people that are having a horrendous time with a the bureaucracy in finding a placement. You have to fight, fight and fight...When he was assessed there was this sense that gee we might have to deal with this a long time in the community. Absolutely, but I really pushed Home Care. Once that was decided I made it very clear to them that they would put in 24 hour service into the Lodge because they always brag about that kind of stuff. And then they backed off...

Dad had had many assessments but he had had one with Homecare and that's when they decided OK yes dad is a candidate for Wedman and they put his name on the top of the list to get him fairly soon because I tend to be the kind that I am going to pressure somebody too. I have to fight for dad because dad can't fight for himself. I am not going to put his name on a list and let them work on it. I am going to harass them if I have to get dad where I would like him to be. They put him on the top of the list and then when Wedman had an opening...

I said, when will the papers be sent over? One week she said, they will be there by Friday and when I waited a whole week to phone... and they said oh we don't have them yet. So I phoned her and I said well you said Friday, a week ago. She said well it's been busy.... But this was my mother and this is not a cog in the wheel. This is my mother.

In addition to contacting the appropriate professionals, caregivers also must inform others such as family members of their decision. This is not always an easy undertaking and can be quite emotionally draining if support is not received. To convince her sister who was visiting from out of province, one caregiver placed literature on Alzheimer's disease in her sister's room and had her father stay with her sister's family for the weekend. By the second day she said her sister could clearly see how confused her father was and that long term care was necessary.

Time and Location of Placement

Due to the nature of the placement system, a date when placement will occur is not given when applying for a long term care bed. All caregivers in this study were uncertain when the placement event would occur. Having reached a time when caregiving was becoming very difficult, the anticipation of having to hold on for an uncertain period of time was stressful.

> *I thought, my God, if I have to wait six months with her doing what she did last night and I hadn't any sleep in three days. I would be in real trouble. The one thing I didn't want, because having heart trouble you know, you don't really want to drop dead on your partner who is needing you.*

However, most describe being "caught by surprise" when they received the eventual call for placement. A long wait, as much as a year, was anticipated due to recent budgetary cut backs in health care funding and the limited number of long term care beds. When the call was received sooner than expected, a sense of unpreparedness prevailed. In addition, they felt they had "no choice" whether or not to take the offered placement. If they turned down the bed at this time, they faced the uncertainty about when another bed would become available.

Because when the nurse mentioned to me that she was ready for permanent placement I really had my doubts but I agreed that her name should be put down because the nurse said 'you know- it could be six months- it could be two years depending on the institution. We have got that number of beds we have to wait for death vacancies'.

You may be able to say, if there are two places available at this nursing home and this nursing home, you may be able to say well I like this one better but they give you like hours... type thing. When they say dad's there, they said you have got three days. We don't have a lot of time here and I'd like thirty days notice. Time to calm down have a panic hissy fit you know and then get on with it. They tell you you have to make a decision now... Everything has to be fast, fast, fast. Then getting dad into the home. There ended up being a bed available for almost a week and a half after that and yet they were rushing so fast.

After finding herself the main caregiver to her mother when her father suddenly passed away, one caregiver states "*... everything was in place and the wheels were grinding pretty fast at that point. So I guess I was lucky in that respect because the wheels had already started to turn. But I was unlucky in the respect that I had no choice but to put her into care immediately or face the unknown. I just didn't know what to do. So we were forced into putting her into care earlier than we really wanted to but I really didn't have any choice.*"

Once caregivers contact the placement agency they are asked to list long term care settings in which they would like the care recipient to be housed. For some, making the "right" choice is a challenge fraught with uncertainty. One caregiver was told to find a suitable nursing home after her mother had been in hospital for several months following a fall, but she was uncertain about her mother's needs.

But you are just kind of thrown in this and I really had trouble when I was given this list of facilities. It was up to me to place her. Well I knew what she was like in the hospital but I hadn't been with her all the time. So to send someone like myself. I have hardly been in the hospital so to walk into a facility and say this is what my mother needs. I found it really really hard because I didn't have the time to go and look at all these facilities and yet I knew it was my responsibility to find some place for mom. But it really throws you for a loop when you know you have to get them out and get them into

another facility and of course health care the way it is now, the waiting lists are horrendous to try and get them into some place.

Another caregiver states *I mean when I first went there to the nursing home and we had been to others before hand but there wasn't any point in choosing the one you wanted your mother to go too because you simply had to take the one that became available once you were on the list. Why spend a lot of time.*

For some the responsibility of finding a nursing home was unclear.

The doctors and the lodge were saying that I had to do the looking myself, and home care was saying no, no.

Even caregivers certain of their placement choice faced uncertainty. As with all caregivers the definite nursing home location is not indicated until the call to the caregiver for admission is received.

Following Through

Once the care recipient's name moves forward in the nursing home system and a suitable bed in a nursing home environment becomes vacant, caregivers are called and asked if they wish to have it held for the care recipient. The caregiver must then decide whether to follow through with the decision of placement. The term "following through" is used because the decision is still held tentatively by the caregivers, even after the care recipient has been in the long term care setting for months.

For many caregivers "preparing with uncertainty", is a stressful and uncertain time. Coming to the difficult decision of placing a relative, and then following through not only involves preparing oneself for the change, but others as well. In turn these preparations are made difficult by the caregivers' uncertainty about the decision,

uncertainty about when placement will occur, and uncertainty about where it will occur.

Finding the Way

Immediately after placement the caregiver embarks upon a journey of "finding the way". The caregiver has to sort through intense emotions, in order to refocus on the caregiving job at hand. Over time the intense emotion diminishes to some degree, however throughout this experience a sense of ongoing loss remains.

In the phase of "finding the way" grief and guilt begin to lessen as caregivers begin to come to terms with the care recipient's reaction and adjustment to placement, the new environment, and the decision itself. As the caregiver begins to "come to terms" with placement increased comfort with the situation is experienced. They are also trying to "find their way" towards a meaningful role in the care recipient's life in the long term care setting. This requires a redefinition of their current role. In redefining their role caregivers redefine their level of involvement and the focus of their caregiving.

Through the Emotions

Immediately after placement and for varying length's of time, caregivers experienced a time of intense emotional feelings. In this study, the main emotions described were grief due to a sense of loss, and guilt for placing their relative in a long term care facility. Intensity of emotions varied, likely due to the caregiver's individual nature, past experience, and quality of the relationship with the care recipient. Sources of loss were related to loss of the care recipient's physical presence, loss of ability to connect with the care recipient, and eventual loss of the

care recipient. Although the emotions lessened with time after placement, many report that these emotions remained and were ongoing.

Loss

Immediately after placement many caregivers experienced intense feeling's of loss and grief. This sense of loss occurred on several levels: at the physical level due to the physical separation and loss of the care recipient to the long term care setting; at the cognitive and emotional level, due to the loss in ability to connect with their spouse or parent because of cognitive decline; and lastly, at the anticipatory level as the caregiver anticipates the imminent loss of the care recipient through ongoing decline in physical and mental health. Placement in a long term care setting serves as a marker for this decline, indicating that the care recipient has deteriorated to the point that they require institutional care.

Many of the caregivers equated placing their family member in a long term care facility with the experience of a loss due to death. All caregivers in this study indicated that they were or had undergone a time of mourning. The examples below speak to the intensity of the emotions experienced.

> *I knew that she was gone from me forever. It's like death but it isn't you know. It's worse than death. I think if she had dropped dead in December I would have been better off now. I probably would have recovered by now.*

A caregiving daughter, drew a parallel in having to prepare her mother's clothes for the nursing home after she was placed, to preparing her father's clothes for his funeral. She forced herself to carry on despite having difficulty completing the task as can be seen in the following statement:

I guess in some ways the mind is trying to adjust to this and protesting just like when somebody has died- this is not right, this is not fair is it- it just wants to shut down and says I don't want to do this,...but it is almost like when my father died. You go to the closet you know it has to be done, and your mind is fighting with yourself...

One caregiver describes how the experience was simultaneously like death and very different from death:

Well I would say it's an emotional situation. You have been living with this person for so long and then the fact that she is no longer with you in your own home surrounding. It's just like a death. Really. The separation is just like, I would say a final blow in a way...some of my friends who have lost their wives have said to me- well you have still got your wife with you even though she is in a world of her own or seems to be. That's probably true. It's altogether different. Altogether... when they say you still have your wife with you. That's probably a plus as far as I am concerned. That definitely is. It's not really a separation like death

Physical loss. With admission to a long term care setting, the caregiver losses the physical presence of the care recipient. The physical "presence" of the care recipient is valued, even if the care recipient has lost the ability to communicate. This is particularly poignant for caregivers, such as the spouses in the study, who lived intimately with the care recipient

There is a price you pay because you wake up and find no one in bed beside you. You wake up... There are times you feel desperately lonely.

A caregiving daughter describes the loss of her mother metaphorically in this excerpt.

Well my brother was up from (his town) last week and so he was going to visit mom on his way out of town. We're emptying the house now...the house she would never let us empty, and he phones up and says he can't find the nursing home. He's been up and down the street and can't find it. So I tell him where it is and he says OK. But I think afterwards well isn't that curious- I mean he can't find his mom, he has lost his mom. She is lost. He is lost. We are all lost.

Loss of connection. The loss of a sense of "connection" with the care recipient is a very difficult loss. Family caregivers are emotionally connected to one another long before the role of caregiver and care recipient evolves. Over the years a bond is formed and includes common memories and experiences. However, due to the care recipient's cognitive impairment, the ability to carry out roles and maintain and nurture connections is diminished or eliminated. Caregivers are the ones left "remembering". Also as indicated by some, the decision to seek placement makes this sense of loss more apparent as the caregivers find themselves without the person they normally would consult in making a major decision.

> *Like after[the] Christmas New Year thing which was awful then she was bright again and she would want to have a conversation... she would want to have a conversation about what is going on in your life. She was there. She was present for that. She had better days and worse days but I mean I really didn't think she had Alzheimer's. But now I think she does. It may simply have come on from the stress of a this. Losing her home and ability to walk.*

> *It is a difficulty because I'll have times where she' ll ask me and I have pictures of my dad and she doesn't know who he is. She remembers him as a young man and I find that very hard. I get very angry. ...I get very angry that she can't remember him and she can't remember when he died and she'll ask me how he died over and over again. I find it difficult to keep relating it.*

Another caregiver describes what occurred after informing her mother that she has breast cancer. *All she said to me was- isn't that too bad when are you going to be well?. And of course you don't know. You know she has never asked me to this day how am I doing.*

> *I think what upsets me is that this man is no longer the father that I knew. There is somebody else in his physical body. You lose that person by millimeters at a time. They have just gone. Sometimes it [is] so very quickly and sometimes it is very slowly. Yeah- it is upsetting.*

The first couple of times- well maybe longer than the first couple of times I went to the nursing home, I would cry. I didn't cry near to the extent of my sister did...I still believe that some of the stuff I have gone through with my daughter's illness has helped me to cope with my father's illness.

I felt an immense loss. And that loss was not just my dad (who passed away) it was my mom as well. I felt like somebody had taken a big support out from underneath me because you always think of your parents as being stronger than you are.

Anticipatory Loss. Some describe placement in a long term care facility as the "beginning of the end", highlighting the fact that the care recipient has reached the stage in their illness where they require formal care, and are unlikely to return to their former self. On many units there are individuals in varying states of cognitive decline. Often seeing these individuals, particularly those at a more advanced stage than the care recipient, serves as a living reminder to the caregiver of "what's next" for the care recipient.

Guilt

For some caregivers feelings of guilt arose at having to place their family member in a long term care setting. Often these feelings of guilt came from two sources: a sense of personal inadequacy at letting the care recipient down, and ambivalence about their decision to place the care recipient.

There was guilt for me because you know I wasn't going to be taking care of my mom full time and maybe it was something that I had to do because it was my mom.

Oh Yeah, I had to cope with the guilt feeling I can't do it, and that's hard.

However not all caregiver experienced guilt. Several caregivers indicated they had no sense of guilt, but rather a sense of relief, in having the care recipient placed. This can be seen in the following examples.

> *I didn't feel guilt about him going into a facility because I knew it was time*

> *...I would never have any guilt about putting somebody who has Alzheimer's Disease or another dementia or any kind of incapacity mentally in any environment where they will be safe. To me that is paramount concern. They have to be safe and you have to do what you need to do to put them in a safe environment. There shouldn't be any guilt involved.*

For these caregivers one might conclude that feelings of guilt are connected to the previously mentioned phase of "realization". Based on their "realization" that safety needs outweigh care recipients independence and autonomy, caregivers are more certain of the decision and guilt is not an issue.

Individual Variation. Caregivers' emotional response likely varied due to individual nature, past experience and quality of the relationship with the care recipient. Three of the caregivers found themselves having to place the care recipient in a long term care facility soon after the death of a parent. It would seem that when the emotional response to placement is compounded by the grief of losing a parent, the experience is more difficult.

Relief

Some caregivers describe a sense of relief after admission of the care recipient to the long term care facility. One caregiver felt relief in having more freedom for herself and being able to come and go from her home as she pleased. For another a sense of relief was felt as soon as her father was placed on a secure unit and she felt

he was out of danger, as wandering was a concern. However, for one caregiver, due to her own illness and the emergent nature of the placement, feelings of relief were delayed, as she needed to get through other emotions before a sense of relief could be experienced.

> *It was a great relief and I needed the time for myself because mother was a constant- I had to spend a lot of time with her. So it was a relief in a lot of ways yes but for awhile I couldn't see that it was a benefit to the degree I do now because I was still too upset with it. I was dealing with my emotions and one thing and another as opposed to all the work I was having to do. Basically for awhile I wouldn't say I saw any relief. It was just a matter of one overshadowing the other one. But now I can... (one year after placement).*

Emotions Diminish in Intensity but Remain

After an individual period of time the strong emotions experienced begin to lessen but, as reported by the caregivers, they never fully go away. These emotions, are closely related to other issues the caregivers find themselves having to come to terms with, as well as to individual make up and life experiences.

> *" I can't think of a worse torture than what I went through. I wouldn't wish it on my worst enemy. It's just a horrible thing to do to you- to take someone you've lived with for 49 years and do that to them. There we are- we get round these things. Things get better. Time heals."*

> *"As her health improved and she adjusted to the placement the guilt eased. The guilt never goes away. Never, never, never goes away but it eases."*

It seems an underlying feeling of grief remains and is contingent on the care recipient's health and well-being. This sense of grief is made more apparent when caregivers are faced with the care recipient's decline, which brings forth a realization to the caregiver of their pending loss.

" I am losing my mom now and when she finally does die it will be a relief because you lose people bit by bit all the time and when these people finally do die it is a relief that they have died and they don't have to suffer anymore. And neither do you have to suffer anymore. So the mourning is done all the time as this illness is going through its stages."

In finding their way, caregivers describe turning to activities that they knew would provide comfort and solace. For some, this was turning to their spiritual faith, attending bible study groups, reading scripture and or visiting with their pastor. Others were supported by family and friends. One caregiver describes returning to his hobbies in this statement:

"I am better now because what I have been able to do is throw myself into my hobbies. I do a lot of writing. I do a lot of painting. I also play the piano and do a lot of music. I keep busy and I go out as often as I can.... if I hadn't had art, music and writing- I would have gone mad."

While trying to find her way, one caregiver who was having a particularly difficult time describes receiving assistance from a nurse at the long term care facility her mother was housed.

" She was right on target and very helpful. I got emotional and she was quite stable. She was able to kind of shepherd me through the stormy waters, so to speak. Help me kind of walking with me during this particular time until I could. It's almost like walking out into deep water and somebody taking you and kind of helping you to tread water until you felt the bottom again. Basically this is the only way I can explain it. It was very good and I was in need of it and, of course at the time I needed it more than I would have probably so much if it happened today."

Coming to Terms

After a stage of intense emotions the caregiver moves to a stage identified as "coming to terms". This is a time when caregivers begin to find their way through the emotional upset, and find themselves having to "come to terms" with the placement

of their family member. By "coming to terms" the caregivers were trying to come to some resolution of the situation. In this study the caregiver's ability to come to terms within the long term care setting was influenced by several interrelated factors. These issues include: the caregiver's ability to "live" with and accept the decision of placement in a long term care facility, the care recipient's adjustment and reaction to placement, and the caregiver's perception of environment suitability. While sorting through these issues the caregiver was also negotiating and determining their role as family caregiver within this new environment. This can be seen in the following statements:

> *"After about 4 months I realized that she had accepted she was there... I think I was concerned about her in the long term care facility. That she might be upset with me for placing her there but there was no indication from her like that... I feel now that she is getting good care in the long term care setting and it has enabled me to get my life together... but I have accepted the fact that she is in there so I am able to look after myself and look after her."*

> *" (re adjustment of CR) Yeah she has. That's home to her. When she is here if I keep her out too long- if I keep her out later than I normally do in the evening she starts to get agitated and wants to go back. She gets tired and wants to go back. So yeah that is home to her that's her familiar surroundings now and that is her comfort zone. A lot of that has to do with the fact that the staff is very good. They have been wonderful. They are very welcoming you know, tease her and joke around and things like that and she does feel comfortable there. But I think, my friend was right- I was not doing her any good by going daily because I was this lifeline that she was hanging on to and hanging on to and I wasn't giving her the space that she needed to become adjusted to that... When I made that break, and I think I had to be comfortable myself in order to do that then she did way better."*

Coming to Terms with the Decision

One might assume that the decision to place the care recipient in a long term care setting was made when the care recipient entered the facility. However for some

caregivers this is only partly true and several revisited their decision to place. If the caregiver had difficulties with the care recipient's response to care or the environment suitability, feelings of guilt arose and a they questioned the placement decision.

> *" I think I saw placement as 'oh thank goodness, you know, now there is going to be someone to take care of her' but instead of seeing an improvement what I saw was a deterioration physically." " yes it did (brought questions to mind) Did we do the right thing? Should we have tried it some other way? What could we have done? So I mean there was a lot of guilt there on my part as to-because it was so fast and at a time when it was difficult for everybody"*

A caregiving daughter felt the decision to place her mother was made easier because of her physical disability

> *"because I can see she doesn't have use of the upper part of her arms. She can't look after herself as well as she could before she had the fall. With each step- it probably in some respects did help me because I knew she couldn't handle being at home by herself... she needs to be institutionalized but with her being what I think is borderline at the moment. This is what is hard to accept. You can see her in a home atmosphere somewhere with care and you know there isn't the facility out there..."*

Alternatively one caregiver questioned his decision to place when his wife began to improve:

> *" I know personally if I went into the long term care setting, good though it is, if I were on that ward she is in, even being normal mentally to start with, within two weeks I would be an idiot... I now feel guilty at taking her back there. I've seen such an improvement." " on the other hand she still has bad nights...so if it weren't for that I would take her home again."*

Other caregivers indicated a certainty that they made the "right" decision, in part due to the realization that the care recipient requires an institutional level care, that no other options are available, and that care provided is satisfactory. In addition those

caregivers who seemed more certain about their decision, also seemed more ready to come to terms with the care recipient's response to placement and the environment.

> *" It was a tough decision for me to make. In retrospect I would say that it's the best thing that I did because I wasn't able to care for her at home on a 24 hour basis and knowing that she was being looked after in the night or evening when I wasn't there sort of took a load off my mind" " I feel now that she is getting good care in the long term facility and it has enabled me to get my life together"*

Coming to Terms with the Care Recipient's Response to Placement

Of great concern to the caregiver, is the care recipient's response to their new living situation in the long term care setting. Caregivers continue to monitor the care recipient's health and well being, noting their reaction to placement and adjustment to the move. The comfort level of the care recipient has a direct effect on the caregiver's level of comfort. As the care recipient is seen as adjusting to or improving in their new situation, the caregiver becomes more comfortable and confident about the placement decision. In the following example, a caregiver describes her response to her mother's reaction to placement.

> *I would be waking up- when we first put my mother in there I wasn't sleeping more than three or four hours a night because I was waking up all upset because she was upset. Even though I had logically told myself that she was safe and secure, well fed, clean, people are looking after her. She's not happy that was difficult to adjust to.*

> *It is very difficult. I keep thinking I got through my visit today and she has not asked about when I am going home. I don't know whether it's mental telepathy or what in the next breath she asks when am I going home, when am I getting out of here. There is nothing wrong with me.*

In this study, adding to the caregiver's difficulty in "coming to terms", seven caregivers out of the ten reported a sharp decline in the care recipient's health shortly

after placement. The hope of the caregiver is to find the best possible solution for their caregiving dilemma, and in these cases it was placement. The timing of the care recipient's decline in turn caused the caregiver to question the suitability of the environment and the decision of placement.

After her mother was placed on a locked cognitively impaired unit one caregiver stated " *I was so concerned about her maintaining what little health she had at the moment"*

Another states:

> *"I question the decision a lot probably because she has declined so much since she has entered the nursing home and then had a fall, she's not the same and never will be."*

One caregiver's case is made more complex due to his wife's extremely rapid decline. In explaining his wife's decline he states:

> *I got the impression- she is a very practical person is my wife, not like me. She's not emotional at all and she would say to herself. Well this is it. This is what I have got to put up with. This is where I have come to. She shut everything else out. I think that's what she did.*

A caregiver's ability to "come to terms" may be enhanced by an improvement in the care recipient's health status, increasing the caregivers ability to reach a certain level of comfort, as can be seen in the following:

> *I am much better than I was about the first two weeks for a number of reasons. Number one; my mother isn't as upset obviously. She has adjusted to the place and she seems to see a lot of positive things about it. Sometimes she will say well its not the same as your own home but she doesn't start to cry, and she doesn't get emotional about it. So I am much better the last two or three weeks because her phone calls are not distraught anymore and crying and being upset.*

One caregiver describes how she took the initiative as she saw her mother actively take part in her own decline, in an attempt to "come to terms":

> *So I said to her this was not what we want, but we will go along with it but if you don't want it then please cooperate with the staff, eat, take your fluids, take your pills, just cooperate. Because I said this is making it tough on me, and then of course she accused me of not caring I said 'yes I don't care, I have just been crying my insides out for the last several days for nothing'. And I had because she was tearing me up because basically I knew if this went on that I had to come to terms with that. It was tough.*

In one caregiver's case, her father's decline shortly after placement further convinced her that the placement was necessary. She believed that if the decline had occurred while they were trying to provide care in the community they would have experienced greater difficulties. She believes that as he did not have his wife guiding and cueing him through activities, his actual capabilities became apparent.

One caregiver's wife's improvement after several months of sharp decline, did not increase his comfort level or enhance his ability to come to terms. Instead, with her improvement, he questioned his decision and wondered whether the setting continued to be suitable.

Coming to Terms with the Environment

Upon entering the long term care facility caregivers are struck with the differences between the home environment and a larger institution like a long term care setting. In this environment caregivers find themselves having to adjust to the physical setting, other patients, and staff in an effort to come to terms with this new setting and redefine their role. In turn, issues arise in relation to environment suitability, the

impact of environment on the care recipient's health, and the environment's influence on the caregiver's ability.

> *It is mostly women [patients] and they sort of remind me of birds sitting on the wire- quite thin and gnarly-like, their hands holding onto their chair like birds and the big eyes looking, looking. They just spend a lot of time looking. I mean it is a very strange place- long term care. It is a strange place.*

Environment suitability. The long term care setting is often not a first choice but rather one of compromise. If asked, many caregivers will say they would rather the care recipient live in a more home-like setting. In this study some caregivers reported feeling that the care recipient was not quite ready for an institutional setting, particularly as they compared their family member with other patients within this setting. Some caregivers commented on the environment in relation to the care recipient's health, almost defining their state of health by the environment in which they are housed. If an "ill fit" was perceived between the environment and the caregiver's idea of the care recipient's abilities or state of health, then concern arose about suitability of the environment.

> *I thought gosh she must have slipped terribly from the Glenrose to coming to the nursing home in a matter of hours. Why was she on this kind of unit?" " Whether it would have been as hard for me if she had just gone to the unit she is in now, but it was this locked unit and it just threw me for a loop. It just really threw me for a loop. I phoned my goddaughter who is an RN and asked what is my next stage. I can't see my mother being there.*

> *I went with them to the hospital and I just felt my wife wasn't ready for that-for an institution of that nature at this time. It just broke my heart to see the residents of the facility in the state of health that they were in. I didn't think that my wife was at that stage of health they were in.*

...he has deteriorated at the nursing home, the staff can only do so much there. Much better philosophy atmosphere at McConnell Place where they are encouraged to keep active. At his present nursing home they are just given basic care, good basic care mind you but that's it.

So if you have to place someone in a facility that is not for Alzheimer's Disease, I think to face a whole different set of situations because here you have maybe a person who doesn't quite fit into their environment and you have staff that may not be accustomed to people with that problem.

One daughter described her sense of relief at her mother being placed and was beginning to feel that "this might work". Then one week after admission her mother fell and fractured her pelvis, greatly shaking her trust in the suitability of the setting and correctness of her decision.

that's true (mom's fall) made it difficult for me (to adjust) Yeah. Because what is this place? what is this dangerous place I have moved her to? It was supposed to be a safe place and she fell. And I mean they warned me. You know your mother is at risk because she is shaky.

Commenting on the benefits of the care recipient living in a long term care setting and their satisfaction with care provided several caregivers seemed to indicate a "coming to terms" with the environment.

Dad is in a safe place now. They look after him well. He is in an excellent facility. It wasn't one we chose...It is a good facility. They are good with him. He accepts care more readily from them than he did from us... I think more and more he doesn't want to be bothered communicating with people. He is just withdrawn. I think too, if he was at home still he would be totally isolated. This way because he is in a care facility he is forced to have contact with people whether he wants to or not. There are some activities there that he can take part in..

Another caregiver is hesitant but gives an indication of " coming to terms":

Your options are limited. I guess you take the best you can. I know that in the facility the staff are very caring and I know that in the

facility that in some of them you hear stories where maybe they are not. So I am lucky in that respect. They are all wonderful and I keep in close contact with the staff members and talk to them as much as I can.

One may come to terms with one aspect, but still have difficulty with another, as in the case of one caregiver who was happy with the environment, but upset about her mother's reaction.

She is in absolutely the best place we could get her in for her condition. So logically you accept but it is very difficult to handle when she is crying and she doesn't want to stay there- she wants to go home.

Interestingly, one caregiver felt that another patient had impacted her mother's health. Another patient who had a positive influence was moved thus contributing to the subsequent decline in her mother.

Mom has really gone down hill skill wise and socially because this lady (another patient) has moved... mom has definitely gone down hill since this (placement) has happened. From that perspective placing them all together is not a good idea I don't think.

Several caregivers in the study were health care providers and seemed to be more comfortable in the long term care setting. Several others had never even entered a nursing home until after their family member was placed. They found this to be a great adjustment that one described as a "shock".

A different experience. Of the informants, one seemed the most unprepared for her mother's placement. Her mother was placed on an emergency basis when the caregiver was rushed to hospital. A sense of realization, the first phase of the process described in this study was not reached until many months after placement had occurred. This realization came about after she attended a care conference where her

mother's situation was clearly outlined. She admits to having very little understanding of her mother's situation prior to the conference. The conference occurred between interview one and two in this study, allowing the researcher the opportunity to document this change in view.

> *... for other people who are in there that are in this position it might be just as well when they take them there to bring these things to mind. Sit down and have a conference with them and outline these. Better still put it on a piece of paper. I find that for me when you are in a state of mourning almost, you are kicking yourself and you are on a guilt trip these things don't seem to stick. If you discuss it and then hand them a piece of paper and they can go home and have a look. They can reinforce those things and these people that have been caregivers can get off this guilt trip and quit kicking their heads basically walking on themselves. They can come out of this thing and start moving forward. That way you are not any good to yourself. You are not any good to the people you are trying to caregive either... what was the other a thing I found out oh -the disorientation. They can come to realize you've done all that you can there is no need for the guilt trip, there is no need to try and figure out where you are going wrong here or what else you could have done. You can get off that treadmill and get on with your life and let them get on with theirs too. .. Yeah I was on that treadmill. Basically I was still on that treadmill until I went to this family thing where I found out a little bit more about it. Then it was like somebody had turned the light on. You were in a dark room and somebody came in a turned the light on and said what are you sitting in the dark for, turn the light on. When you are on this treadmill or in this mode you don't seem to- you have to have somebody outside or something outside that will bring you to that point of waking up to what is going on. I know I have had people talk to me several times. My girlfriend...I would agree 100% but some emergency would come up and all the things she had told me would be gone and forgotten"*

One could surmise from this caregiver's experience that realization, the first phase identified in this process, is a necessary step in "finding the way" and adjusting to the nursing home placement. Although she faced limitations and a crisis with her own hospitalization, she had not recognized that her mother's care needs were beyond her

ability. Safety was not a grave concern at that time. However with the care conference, her mother's abilities and cognitive situation were made very clear. Coupled with her slow recovery of health she realized that her mother's care needs were beyond her ability. This decreased her sense of guilt and grief, and allowed her to consider how she could care for her mother in the long term care setting.

As the caregivers "came to terms" with the care recipient's response to placement and the environment, they became confident with the decision. Indications that a caregiver had come terms, included acknowledgment that the care recipient required long term care, that they were satisfied with the care provided, made positive comments about the long term care facility, and perceived their emotional situation was improving rather than staying the same or worsening. Caregivers may easily come to terms with a one aspect of this changed situation, but have difficulty with another. For example, those caregivers who have worked in the health field seemed to have fewer difficulties coming to terms with the long term care environment, whereas some caregivers found it more distressing. Positive comments of satisfaction were not seen as readily with three informants, and these caregivers seemed to have the most difficulty "coming to terms". The nature of their difficulties varied. For example one had difficulty with his wife's changing state and his own emotional reaction; another was dissatisfied with the distance to the nursing home; and yet another was uncertain of the environment's suitability due to her mother's fall and fractured hip shortly after admission.

Redefining One's Caregiving Role

Throughout the entire process the caregiving role to some degree is being redefined. Caregivers are redefining their role in terms of the care recipient's decline in ability and their own ability to care for them in the community and later in the long term care setting. As caregivers begin to "find the way" the role they wish to undertake becomes more clearly defined. In redefining their caregiving role caregivers establish their caregiving boundaries and focus. For example after she had placed her mother, one caregiver began redefining her caregiving role as illustrated:

> *It is a big relief. It is a big relief for sure. Definitely. But it is so like so now what do I do? There is that. How can I be of service to her. What can I do now. I am still her advocate. But I wonder if that is all that I can do now. And then I think that makes me sad that there couldn't be something else.*

With a lessening of emotions, caregivers then review their role and relationship with the care recipient. They are freer in a sense to address issues at hand and to more clearly determine and redefine the role they wish to play. This redefinition is strongly influenced by caregivers' experience in the phase of "finding the way". An analogy for this relationship is two dance partners: one representing the early stages in "finding the way", the other representing "redefining one's caregiving role". Each acts upon the other's movements. Redefining the caregiving role includes redefining the focus of their caregiving and redefining the boundaries of care.

Caregiving Focus

In redefining their caregiving role caregivers also redetermined their focus as a caregiver. In coming to terms with the many recent changes and adjustments, they

were able to more clearly identify and determine the type of involvement and focus to which their caregiving energies would be directed. Many caregivers in this study contend that some aspects of caregiving such as the sense of obligation and concern remain unchanged from caregiving in the community. However as much of the physical care was taken over by the staff of the facility, many of the caregivers limited the physical assistance they gave and focused on the emotional health and well being of the care recipient.

Emotional Health and Maintaining a Connection

After placement more caregivers emphasize the emotional health and well being of the care recipient particularly in light of the care recipient's ongoing decline. In addition, with more time on their hands, caregivers are also able to redirect attention to themselves.

> *I know he doesn't remember if we take him out for a walk or take him out to a mall for lunch or ice cream or look at a family album. But I have to focus in and say for the moment this makes a difference in his life. I am always thinking about those things how can I make his life the best possible life that's available to him now.*

> *I want the quality of the visits to be good and meaningful especially as dad is deteriorating.*

> *Let's appreciate what she had got today, if it happens. Because with Alzheimer's Disease she could be like this ...or she could be the same for the next five years.*

One caregiver seemed better able to redefine her caregiving focus once her mother's cognitive situation clarified.

> (the information) *just makes it easier in the fact that I don't feel when she gets into this- I don't have to feel guilty if she is being lonely or some other thing. I don't have to feel guilty that she is there. I know that she is in a facility that is best suited to her and so I don't*

have to go on a guilt trip. I can get off my treadmill. I am better able to visit with her and talk with her and even though it may not be 100% the truth. If that's what she wants to hear I can give it to her. If it's going to make her happy and keep her in a positive frame of mind.

Another caregiver states:

Dad's happy. I really think it's because he knows he is loved. They may not have their minds but they need to know-they are still loved. They may loose all their ability to talk and never utter a word but hold them, caress them, tell them you love them. Be there they know that. It is like you would talk to a person in a coma. They may not know or be aware that you are talking but their spirit or their soul knows that you are talking to them. I don't understand all the intricacies of it but it so important to be there for the people.

In the following statement, a caregiver who had placed her mother five weeks prior, describes how she began to redefine her caregiving role in the long term care setting. She determined that her focus would be her mother's emotional care and then selected the activities she would engage in to support this focus.

Once that is finished (selling her mother's home) our main duty and responsibility will be simply to give emotional support by going to see her and things like that...I think it will be mostly going to see her and being supportive, going to special activities they may have there, calling her two or three times a week, that sort of thing.

In light of the care recipient's ongoing decline, often made more apparent by the placement experience, a major focus for most caregivers was maintaining a connection with the care recipient. Caregivers experienced a sense of loss of connection and, in response to the care recipient's decline, they centered on holding onto what is left. They sought to connect or bond with the care recipient, realizing that time was of the essence. Maintaining a connection was not only pursued through

traditional verbal communication, but also through more symbolic means, particularly as the care recipients ability to communicate was diminished.

> *I try to keep our line of communication open. She doesn't get the opportunity to talk much to the people in there... and she has lost the power of conversation- true conversation. I can draw out words from her that refers to whatever we are talking about....I think there-I can't say that there is any hope for her or her improvement in her condition but I like to feel that as long as she recognizes me and recognizes the family that that's one reason why I continue to go there and administer to her needs. It's a link that she can't get from the caregivers there.*

Conversely, a male spouse in the study had difficulty understanding his wife's speech and taped portions of her conversation in order to interpret her communication and maintain the connection. In the following excerpt he beautifully describes this endeavor:

> *Now particularly I feel desperate that I should be doing something. I should be trying to get her to build in what bricks that she still has. It's rather like a beautiful building that has been knocked down into ruins, you know, and walking in there with the, as a contractor knowing that you have got to put this back.*

A caregiving daughter describes how in the past she did not want not her mother's china and now:

> If she had o*ffered it to me I would say- oh no I don't use china. No thanks. But now I have taken it home. So it is like I want something. I want the connection.*

She makes a point of visiting during meal times to eat with her mother to maintain the connection rather than ensure her mother's nutrition

> *... eating with her is still something we can do together.*

During the interviews with the two spousal caregivers momentoes and photos of their wives observed to be strewn over the dining room tables. One caregiver was in the process of compiling a photo album of his wife for his children. Another says he brings old momentoes and her diaries to the hospital and reads from them as he often receives a response. As well, one caregiving spouse carries in his wallet a hand written note of his wife's stating " *come home soon. I miss you very much"* .

One daughter in the study who identified herself as a major caregiver, although not the main caregiver, did not seem as focused on maintaining the connection. She however continues to visit weekly, maintaining an interest in her father's activities and progress. As with several other caregivers in this study, her father doesn't always recognize her when she visits, and seems to be withdrawing. In the past she says that her father was always independent and had difficulty expressing his emotions.

Redefining the Boundaries of Caregiving

Caregiving boundaries are renegotiated and redetermined. Caregivers decide what they can and cannot do and what they will and will not do. The definition of boundaries is greatly influenced by the caregiver's level of comfort and experience through the early stages of "finding the way", their other obligations, and their past experiences. Boundaries to be redefined are frequency of contact, and level of involvement.

The following excerpts indicate that caregivers had to consider their caregiving role in relation to other roles and obligations. As one caregiver states:

> *This sandwich generation stuff is not junk, it's real. My son and daughter have a handicapped child and I want to help out when a I can...so I have that, I want to work, and I have dad to look after.*

So I already give as much as I can give right now just with my mom, dad, and my church. I have nothing more to give and I have to sit back and say no I am not going to answer the phone. I am going to watch TV. I am going to treat myself.

In redefining her boundaries another states:

I chose a day (to visit) so that I would make it clear to everybody else in my outside life- don't bother me on Thursdays this is my visiting day for dad. I will not work, I will not do this- I will not do that. Unless it is a very serious emergency and it had better be an emergency.

In terms of level of involvement one caregiver states:

You are still very much involved. I have taken it upon myself to be involved... So I still feel that I am very much a part of her life as much as I can and partake as much as she can without being detrimental to her health.

One caregiver in describing the events immediately after placement, begins to define boundaries in the following statement:

Anyway the next two weeks were very difficult (after she was placed) because she would keep phoning and crying that she wanted out. She did not want to stay there and finally I actually did something that was rather unusual for me. I actually got a display phone, so that I would know the call was coming from her and what I would do is I would not answer the phone. I would leave it for three or four hours when I figured she had calmed down and then phone her so that I was in control of the phone call. Usually by that time she had calmed down. She had not taken the initiative to call so in cases was in a better frame of mind and I would chat with her...even now and it has been about five weeks she is much better, but even now I initiate the phone call.

Frequency of visits. In establishing their level of involvement, caregivers must decide the amount of time and the frequency with which they wish to visit the care recipient. In this study several caregivers followed a pattern of intense frequent visits initially after placement, often daily for several months, and then reduced visits to

several times per week or once per week. This readjustment, in many cases signaled increased ease and "coming to terms"; the feeling that the care recipient could manage without them. Other caregivers such as the spouses in the study continued to visit daily, finding this visiting pattern satisfactory for their situation.

One caregiver described how her visiting pattern was influenced by those close to her, even though she felt her mother was not adjusting to the environment.

> *I was going daily. I was just exhausted because I was going everyday... I guess I tried to take over where my dad had left off and being very protective and gradually ... I remember my friend saying to me- you know you can't carry on like this. Why are you going every day? You don't need to be there every day. You are not doing your mom any favor because she has to get used to this environment and she wasn't. She was just waiting for me to walk through the door. So I listened and my husband told me the same thing so I backed off and things got a little bit better." " I spent a lot of time there and gradually pulled out as my comfort level got better.*

Initially she kept in close contact with her mother, visited daily, until her comfort level increased and she felt the need to "cut the apron strings". She sensed that her visits were affecting her mother's ability to adapt to her new environment. Another caregiver describes how changing the frequency of visits was an adjustment.

> *I go once a week now and it feels a big space between visits. Because I was I was used to going twice a week but then we took a holiday... and when I came back I said I would just come in once a week because it is enough and I have to start reclaiming my own life which is waiting to be reclaimed as I have less responsibility and now and I need attention for myself.*

In one daughter's situation, the frequency of visits is related to care recipient response.

> *I realized on the weekends I was going twice a day but it took me about a month or so to realize that she didn't know that I had been there... she never said oh you are here again kind of thing. I would*

remind her that I was there a second time and I thought you know -if I am there once a day- that's probably the best I can do so because she is not sitting there waiting for me to come. And that frees up my time considerably.

The two spousal caregivers in this study maintained a fairly regular pattern of visiting frequently. In fact the oldest participant at 82 years, visits his wife twice daily to assist with meals.

Well yes I feel that I owe it to her and I have the time to spend with her as far as I'm concerned, if I need a break I can always get together with some of my friends... Although shall I say it's borrowed time for me to take time to go ... that's secondary to going to the hospital and looking after my wife.

Level and type of involvement in care. Upon admission to the long term care facility many physical care tasks are taken over by the facility staff, that some caregivers performed in the community. Although some caregivers turn over all aspects of physical care, others select care activities that they can and will still provide. In this study all caregivers, regardless of the degree or type of care provided, continued in the roles of advocate, historian, and monitor.

Family caregiving roles in the community and within the long term care setting are not always apparent to the caregiver. The part they will play in the life of an ailing family member must be determined. This determination involves observation, exploration, negotiation, and learning on the part of the caregiver. In this study determining caregiving activities within the long term care setting was greatly influenced by the environment, the caregivers' past experiences, and their caregiving focus.

Well like you say there are a lot of people involved. I have just learned to ask.

One caregiver, in her role as monitor and advocate, describes her adjustment in the following statement:

...I'm always having to catch up , I feel like I'm trying to catch up as another thing happens. I just want everything to stay the same for awhile. I'm getting better though I know now what kind of care to expect, and what [one] would consider negligence. Whereas before I would see something that would concern me and I should just wonder "is that something I should be worried about or is it just me. I also learned how to bring it up. I had to learn how to tell them something, who to tell it to. I learned about myself and the way I handle things and how in some ways it had to be handled differently.

One of the most involved caregivers in the study describes asking what care he could provide:

They suggested that it was quite appropriate for me to go there and feed her and give any extra care that I felt she would like or that she needed and so I have accepted that and I also have made myself available to others in there. I sort of volunteer with serving the food. I put the food trays for other people and put on their aprons and just give a little extra you might say to the facility there just because I want to do it and because I care about people.

In determining the level of involvement, through observation and exploration, activities may be undertaken to fill a perceived void and ensure that the level of care the care recipient receives is suitable.

I feed her lunch because she can't feed herself and I know that the caregivers [staff] are under stress without taking the time to feed her because she is a rather slow eater and with the Alzheimer's situation affecting the brain as it does her response to the feeding is somewhat slow. .. I was afraid that she might have to go on an IV to get her nourishment but we persisted..."

As monitor and advocate, one caregiver noted her mother was on a pureed diet, which she believed was unnecessary. This reinforced her sense that she was needed as caregiver.

> *But I often wonder if there wasn't someone like myself who's there on a daily basis who is watching things. There must be a lot of people in these facilities who don't have anyone and does it just continue, and continue, and continue without anyone reassessing each persons needs.*

Several caregivers mentioned the care recipient's involvement in social activities as an indication that they are beginning to settle into their environment. One caregiver was concerned that her mother wasn't taking part in the social activities offered. To smooth the way, she made a point of accompanying her mother in the hope that she would eventually feel comfortable enough to go alone.

> *But she is so lonely and it is very lonely. If I could get her interested in the things that they are doing at the hospital. Not everyday, but just something to look forward too. I think once she started and it would certainly be helpful for me too because then I know that she did get out today. She did see other things rather than sitting in that room all the time.*

After years of caregiving, many tasks were automatic and habitual for one caregiver. But once her mother was placed she turned most of the physical aspects of care over to the facility staff. In doing so she had to "force" herself not to direct or take over for she states "*you don't take the wheel away from the bus driver*".

The level and type of caregiving the caregivers assumed was influenced by their goal to enhance the care recipient's quality of life and the environment and staff in the long term care facility. For example, one caregiver stated how she wished to maintain

her father's dignity as much as possible. As she became comfortable in the new environment her focus can be seen in this statement:

> *Every time I went there I would straighten up his room. Now I don't I walk in the room if the room is a mess-no big deal. Because why should I straighten it if he is just going to unstraighten it. Maybe he doesn't like it the way I am doing it... I felt at first that oh I had to keep it nice for them and everybody else.*

Environmental influences can include the physical setup of the long term care setting, the facility staff including those at the bedside and those making the policies, and other patients. One caregiver made a point of taking her mother off the unit to the cafeteria to visit because she found the environment difficult. Another caregiver also felt her mother needed to be away from that setting, so she often took her mother out for strolls, and meals to a nearby cafe. One caregiver could only visit weekly because of the distance from her home to the long term care facility. This was not as frequent as she felt was needed to carry out her caregiving role satisfactorily.

> *I don't even know you know, if my dad would stay at a nursing home closer whether it would be any easier. But I would have the satisfaction of knowing that I could go more frequently to make sure that he is eating better. You know they just don't have the staff to sit with him and coax him. When we are there he eats very, very well and he has dropped a lot of weight...Now it has gotten to the point where we plan a visit very near his meals because I want to stay there and help him because he eats better if I am there. Wouldn't it be nice if I could get him closer I could go there maybe 3 or 4 times per week. But I don't think that's going to happen and that makes me very sad.*

Within the environment of a long term care setting, facility staff are a key component. They set the tone of the atmosphere within which the caregiving takes place. Caregivers often interact with staff to gain information, negotiate care issues, determine what has and has not taken place, and establish what they can do or how

they should proceed. For example one caregiver described how forming a relationship and getting to know the staff translated into better care for her mother.

> *I can approach them about anything. I would have no problem about approaching them about anything positive or negative. Because you build up that relationship and you go from there. You just can't go in there and stand there and complain like a lot of people do.*

Another described her hesitation in asking about test results, when she encountered a new nurse on duty:

> *I make a point of seeking out the nurse in charge every time I visit and ask how everything is going, except the other day when there was someone there that I didn't know so I didn't ask. Even though I'm not sure I want to hear anything bad.*

Confusion arises when communication and expectations between family caregivers and staff is not clear. An example can be seen in the following comments:

> *I asked one girl, I said is it up to me to make sure Dad still has soap and shampoo and things and one girl said yes and then I asked another girl and she said no, the day staff will let you know. And yet they don't. They have four people in one half and four in the other for two girls so they don't let me know sometimes.*

Redirecting attention to self. Caring for a person with Alzheimer's Disease in the community can require a great deal of the caregiver's time and energy. Often little time is left for themselves, and the care recipient's needs take priority over the caregiver's needs. For caregivers in this study, a positive result of placement was regaining the ability and opportunity to refocus on their own needs. In addition to seeking out activities for solace and comfort, as mentioned in "coming to terms", caregivers used their increased time and energy to more fully undertake activities to

care for self. When asked what is different since the care recipient was placed, caregivers explain:

> *I think I have been relieved of the technical necessity of dealing with her. I can't consider myself in any shape or form the same (caregiver) as I was before she went in. I have been freed to do a lot of things that I couldn't contemplate before. The difference is that you are able to pursue things and focus more on yourself.*

> *Well I'm looking after myself more, looking after my own health. You know the day to day things, like making sure I drink eight glasses of water a day. Well I found myself asking have you had had your glass of water lately? where as before I barely remembered to brush my teeth because I was so tired and had a lot on my mind.*

Of the caregivers in this study, the caregiver whose health was the most affected by caregiving states:

> *From the time that the folks got sick I just plain forgot about me. I just didn't exist...This is the thing I have learned[while in hospital] that I have to look after me now and I have to have something that is a positive thing...(my chiropractor) said you need to be good to yourself for awhile. He says you haven't been for so long and he says you need it... You have to take care of yourself or you will end up the same way again. That's what I have to do. I am just taking his advice-changing my diet and changing my attitude to be on top of it and as positive as possible.*

Carrying On with Ongoing Change

As the caregivers find their way through and redefine their caregiving role, they begin to enter the phase of "Carrying On with Ongoing Change" . Carrying on is also a matter of surviving the continuing changes and ongoing decline exhibited by the care recipient. In this phase the caregiver is beginning to establish a newly determined caregiving role and routines are established. Establishing a routine can seen in the following statement:

When I accepted the fact that this was the place for her. It took two or three months before I would accept the fact that she was in the facility and they were giving her the care that I couldn't give her at home. That sort of relieved me... now I would say it is just a matter of routine.

An aspect that remains constant for the caregivers throughout this entire process is having to deal with ongoing change and loss due to the care recipient's decline in health and ability.

Dale the head nurse said- oh well, she has just settled in that's the reason she is so much better. Why should she go like this for five months then suddenly settle in in a couple of weeks. And she laughs now and smiles. This is completely new. I am told this is the nature of the beast... It's got me very frustrated. This latest improvement...

We got to the stage where she was adjusting and I adjusted and everything was doing well. Now we are on the downhill path again because her skills are going downhill and I really think as we said before, since they put all the AD patients in the floor and you are constantly smacked in the eye with it as soon as you go through the elevator door.

Everytime we go there-every time we go now to see him, which is once a week, almost everytime he is a little bit different. He is more withdrawn. He doesn't always recognize mom and I... In a sense it will never be over until he dies. You live with it every time you go to see him there is a change.

Not all caregivers in this study can be said to have entirely "come to terms", "redefined their caregiving role", and comfortably moved towards the phase of "carrying on". One might assume that the caregivers who placed their family member first would have entered a phase of "carrying on". Although true for some, this was not the case for all. The study criteria specified inclusion of participants who had placed their relative in long term care within the past 12 months. Informants who participated had placed a family member between five weeks and 12 months prior to

initiation of the study. Thus a variation was expected and several informants seemed to be still "coming to terms".

Summary

In conclusion, the findings based on interviews with ten caregivers who had recently placed a family member with Alzheimer's Disease in a long term care facility, revealed the process of "redefining one's caregiving role". This process attempts to portray the family caregiver's experiences before, during, and after placing a relative in a long term care facility. The process includes two phases pre placement and two phases post placement, each involving several stages. Before placement of the care recipient in a long term care facility the caregiver moves through a phase of "realization" and "preparing with uncertainty". After placement, the caregiver enters the phase of " finding the way". As they begin to "come to terms" with the new circumstance, and "redefine their caregiving role" they move to the final phase identified as "carrying on with ongoing change". Ultimately the caregiver's ability to redefine their caregiving role is dependent upon their ability to come to terms with the decision itself, and care recipient's reaction to placement and the long term care environment.

CHAPTER V: DISCUSSION

The findings of this study uncovered and described the process of " redefining one's caregiving role" when a relative is placed in long term care. The study examined the placement experience from an emic viewpoint to capture the transition caregivers face, shedding light on an experience which has remained in the shadows.

In this chapter the findings are discussed in relation to similarities with other research as well as the unique contribution of the study to our understanding of caregivers' experience. For clarity, this discussion is organized in relation to the categories of preplacement, the decision to place, and experience immediately after placement. Finally the implications of the findings for nursing practice, research and education will be examined.

Several qualitative research studies describe the caregiving experience from the time when the caregiver assumes this role, to the time when they either turn over care to a long term care facility or the care recipient dies (Wilson, 1989; Lindgren, 1993; Wuest, Ericson & Stern, 1993). Only a few studies were found that addressed the caregiving experience and placement (Morgan & Zinmmerman, 1990, Willoughby & Keating, 1991; Duncan, 1992). Some would suggest placement is a phase within the ongoing caregiving experience. This study thoroughly examines, the caregivers' perspective of their experience before, during, and after placement has occurred, as well as the changes which take place. The findings of this study, about the experience of placement and the related transition, suggest many emotional changes occur and caregiving adjustments are made by the caregiver at this time.

Preplacement

Caregiving in the home can present many challenges. In the "realizing" phase of this study when caregivers were "facing limitations", they dealt with and attempted to find solutions to these challenges. The process can be stressful and disheartening if not met with the anticipated outcome. It was a precursor to situations in which the scales were tipped and they came to a decision to place their relative. "Going through it", is the second stage of caregiving as described in Wilson's (1989) study. In this stage caregiving involves the passing of time and dealing with a sequence of problems, using an emergency, trial and error approach, "pushing caregivers to the awareness of their physical erosion and emotional breaking points" (p. 96). Morgan and Zimmerman (1990) found that the stress level of the spousal caregivers in their study was highest just before the decision to place was made. This may be a result of accepting the fact that an ill spouse needed constant supervision and that they could no longer provide the necessary care. Similarly in the phase "realizing", in the present study, the stage of "tipping the scales" occurs when caregivers realize that the care recipient's needs outweigh abilities and resources.

The Decision to Place

Duncan identified five themes that were crucial in influencing the caregivers decision to place their relative in long term care: an event, health care system characteristics, caregiver-care recipient relationship, support, and options and availability of resources. These themes are similar to several aspects identified by caregivers in this study in the first stage of "facing limitations" where a limitation

may be experienced from the health care system, the caregiver or care recipient, the family or community.

There are conflicting findings in the literature about the importance of a crisis event in triggering caregivers' decision to place a family member in a long term care facility. For example Duncan (1992) indicates that the actual turning point event was not a crisis event. Similarly in "tipping the scales" in the present study, issues of safety were involved. However unlike Duncan's findings, these were related to a crisis event. Wuest, Ericson, and Stern (1994) in their "letting go" phase describe a triggering event, which they define as an event such as a violent act or personal illness that makes the caregiver give up. This is parallel to the accounts of crisis events that were found in "tipping the scales" in the current study. However Wilson (1989) reports that there is no consistent problem that marks the "breaking point of caregiving tolerance", rather it is an "ongoing sequence of problems with the concomitant time pressure of constant care demands that force caregivers to question the consequences for their own lives" (p.97). In the present study, the caregivers' primary concern was the care recipient's health and well-being. If they could have maintained caregiving in the home safely and reasonably, it would have continued regardless of the consequences to themselves. This was evident from the extraordinary lengths, and great personal cost that caregivers incurred before considering placement.

Willoughby and Keating (1991) described a stage of " losing control: accepting the decisions of others", which occurred when caregivers acknowledged that they needed more help to provide adequate care to the care recipient. They also suggest

that no single event causes placement, but rather that it is a result of a build-up of events over time. In the current study, "facing limitations" stage contributed to influencing the eventual decision; compounding and highlighting the difficulties experienced when a crisis arose. In the sequel stage of "tipping the scales", both real and imaginary concerns were brought on by an incident or series of events. It is unclear when exactly they began to arise, but evident that they may develop over time.

Lindgren (1993) found that caregivers' main reason for institutionalizing the care recipient was a physician's recommendation. In this study, eight of the ten caregivers indicated that others influenced the decision or suggested placement. Most often however the influential person was not the physician but someone involved in the care recipient's day to day care such as another family member, lodge personnel, or home care worker. Several caregivers indicated that this suggestion was made in the past, but greeted with dissatisfaction and frustration as it was counter to what they were trying to achieve in the home. This indicates that a readiness or "realization" is required to respond to the suggestions made by others.

Immediately after Placement

Similarities and differences in relation to the current study were also seen in the research studies which addressed caregiving after placement in a long term care facility. In the present study, post placement was a time of great emotional adjustment for the caregiver in which they must "find the way" through the emotion, come to terms, and redefine their caregiving role. Coming to the decision and then following through with it is a time of uncertainty for the caregiver. All caregivers in

this study felt unprepared when the event finally occurred, despite often waiting several months. In Duncan's (1992) study a difference was noted by caregivers between "doing it" and the earlier time of making the decision. She adds there was an overwhelming perception that caregiving came to an abrupt and traumatic end.

An assumption often made is that once placement has occurred caregivers will feel relieved. Although caregivers described feelings of relief the researcher had not anticipated the severity and depth of other emotions expressed in the interviews. The emotions expressed regarding placement, particularly early on, were at times overwhelming as they related their sense of loss, grief and guilt. It would seem that one not only has to be convinced of the decision in the head but also in the heart.

Several qualitative studies relating to the caregiving experience also addressed feelings of loss and guilt. The feelings which occurred immediately after placement are described by Duncan (1992) as an intense emotional "roller coaster". Matthieson (1989) who interviewed daughters who had placed a parent, suffering from various ailments, in a nursing home described unresolved guilt as a consistent theme that recurred even several years after placement. She adds that the daughters found their guilt easier to deal with when their mother suffered from "total cognitive impairment". Similar to findings in this study, caregivers experienced grief due to a sense of loss of parental support and loss of their physical presence, which was different from physical death, ongoing in nature, and recurring with each medical crisis. This sense of loss was a theme described in Parson's (1997) phenomenological study that examined caregiving male's experiences with caring for a mother or spouse with Alzheimer's disease. Again the loss was described as being similar to death as a

result of losing both the person they had once known and the relationship they shared, aspects also identified in the present study. Collins, Liken, King, & Kokinakis (1993), in a large longitudinal study examined the grief experiences of 82 family caregivers, identified themes in the predeath loss experience of "loss of intimacy and familiarity" and "loss of hope for recovery". Similarly, Collins (et al., 1993) found that the quality of this predeath grief was portrayed as "overwhelming" in some cases.

In relation to the stage in this study of "coming to terms", the literature mainly described this in relation to the environment. Little is mentioned regarding the difficulty faced if the care recipient's response to placement is less than ideal. Willoughby and Keating (1991) found that to enter stage four titled "adjusting to a psychiatric institution", the caregiver had to come to terms with the fact that the care recipient was residing in a psychiatric facility. As mentioned the care recipients in Willoughby and Keating's study were often placed in a general nursing home and then moved to a psychiatric facility as their condition worsened. They explain that a move to a facility of this nature can be difficult and traumatic for the family. However this was also seen among many of the caregivers in this study, where care was provided in a variety of long term care facilities.

Morgan and Zimmerman (1990) identified five categories which eased the transition of placement. Again the category "acceptability of the nursing home", is parallel to "coming to terms" with the environment as presented in this study. Morgan and Zimmerman add that proximity of the nursing home was high on the list of the caregiver's priorities. "Once they were able to compare their nursing home

choice favorably with others, the sense of closure seemed to reduce tension" (p. 10), perhaps as a result of coming to terms. The issue of proximity was also of interest to the respondents in the present study. Many mentioned how pleased they were to be within a few minutes drive. In fact, distance was the key issue for one caregiver who felt she was too far away to properly care for her father.

In the present study caregivers often found other residents of the facility a harsh reminder of what the future may hold for their relative. They viewed the behavior of these residents as difficult to get used to. Duncan also reported on this reaction as caregivers were unprepared and " some found the behaviors engulfing, as everywhere they looked they saw the variety, intensity and complexity of Alzheimer's symptoms" (1992 , p. 84).

Duncan (1992) in her study also closely examined the transition associated with placement. She found that once placement occurred there was a shift in the areas of control, involvement, and personal reorganization. She maintains that first there is a shift in purpose, and then in activities. Caregivers changed from being totally responsible for the provision of care to taking a monitoring role. She adds that monitoring served to maintain a relationship with the care recipient, and provided access in evaluating staff. In this study, as caregivers redefined their caregiving role, they also redefined their focus and determined the activities they could assume in this new setting. The researcher found that many not only took on the role of monitor, but as advocate and historian. Several participants, in addition to these roles were comfortable in a more "hands on approach". Ross, Rosenthal & Dawson (1997) in measuring task performance of spousal caregivers after admission to a long term care

facility, found an increase in the number of tasks performed over time. These differences may be an indication of the variation amongst the caregivers and the complexity of the situation that affects how they redefine their role. In fact Willoughby and Keating's (1991) family caregivers reported feeling "left out" and excluded from meaningful caregiving tasks and contact with professionals. This suggests that the desire to redefine the caregiving role must be fostered and supported.

Duncan (1992) found caregivers' visits involved sub issues of frequency and sharing responsibility for visiting. As found in this study spouses visited daily and adult children less often, perhaps two to three times per week. Sharing, which involves children caregivers coordinating visits with siblings and other relatives, was not identified in the present study. Instead, visiting by caregivers who had siblings within the area seemed to be determined in an independent manner.

In the current study, many, in redefining their caregiving role, took particular interest in maintaining a connection with the care recipient. Not only did they verbally indicate that this was an important aspect, many caregiving activities carried this through such as bringing pictures to show the care recipient to stimulate memories, or sharing a meal. In a phenomenological study by Lynch-Sauer (1990) which involved published works from caregivers of persons with Alzheimer's disease, a core theme was "an ever present search for personal connectedness", most often mentioned through touch (p. 9). Touch was not mentioned except when describing physical care tasks. Had observational data of caregiver care recipient interactions been included with interviews, a more comprehensive picture of this experience could have been obtained.

An increased ability to focus on self after placement was identified in the present study in the stage "redefining one's caregiving role". Duncan (1992) reports that caregivers experience a "personal reorganization" immediately after placement. In the current study caregivers also report changes such as being able to focus on themselves, and come and go at will; a freedom not felt by some for years. In most cases caregivers translated this positive experience into more positively carrying out their caregiving role, and feeling stronger and enhanced in their ability to do so.

The final phase identified in this study, "carrying with ongoing change", could only confidently be identified by the researcher in several informants, the majority seemed to be still "coming to terms". While "carrying on" caregivers continued with their newly defined caregiving role. In this phase new routines were established and a greater degree of comfort was achieved. Few studies were found that related to this stage. Willoughby and Keating's (1991) stage of " moving on" relates to a caregiver's experience up to three years after the death of her spouse, where one's life is recaptured (Willoughby, 1988). However for many of the caregiver's in this study, there was no indication that placement of their relative ended their role, or that they wished to slip out of the picture.

Also in the phase of "carrying on with ongoing change", grief to a certain degree is present, influenced by the changes and the decline of the care recipient. Because a time frame of up to 13 months after placement was examined in the current study one cannot speculate as to how the process for caregivers will evolve beyond this period. As indicated many were still "coming to terms", and it is possible that some caregivers may never actually "come to terms" and move on to a more comfortable

level- the last phase of "carrying on with ongoing change". Several elements are at play in this experience. One is adjusting to a new care setting and role while grieving. As indicated by the caregivers however, grief to a certain degree remains and is influenced by caregiver decline. Ponder and Pomeroy (1996), in examining anticipatory grief among caregivers of persons with Alzheimer's disease, who were providing care at home, also found that grief remained throughout this experience. They found that length of time caregiving did not indicate a greater degree of acceptance, "despite a long period of time to engage in anticipatory grieving". In Collin's, Liken, King, & Kokinakis (1993) study, involving a survey of 350 persons who were family caregivers of persons with Alzheimer's disease, nearly half experienced grief repeatedly in response to the losses they encountered in the predeath period. These findings suggest that it is not uncommon, nor confined to the experience of placing a family member in a long term care facility, and that other elements other than time are at play in this grief experience.

Limitations of the Study

Although additional participants were not added to the sample subsequent to identification of key theoretical concepts, there was variation in the characteristics of participating caregivers. Face to face verification of results with study participants was not undertaken, although the entire data set was reviewed in detail for fit with the process and sub components identified from the analysis.

It was assumed by the researcher, that the term "Alzheimer's disease" would be well understood by caregivers and only used if it were indeed appropriate. However this should not have been assumed, as during one interview it became apparent that

the diagnosis was unclear and the term dementia was used to describe the care recipient's situation. The researcher lacked access to information which could confirm or disclaim the diagnosis so the caregiver was included in the study. Although most care recipients had been previously diagnosed with Alzheimer's disease several care recipient's were diagnosed near to or upon the time of admission. Caregivers at this time were not only dealing with placement, but also with the diagnosis of a fatal incurable disease.

Implications for Nursing Practice

Because nursing involves support of families and family caregivers, whether in the community, in an acute care facility during a medical crisis, or in a long term care facility, nurses must be knowledgeable about caregivers' daily experience. Without understanding of the personal meaning of the experience for caregivers, nursing's efforts may prove ineffective or inadequate, potentially adding to the caregiver's frustration and difficulties.

All caregivers face some degree of limitation. However as described in the first phase of "realizing", as time passes and events occur, certain caregivers move toward the decision of placement. In being more aware of the impact of the limitations that caregiver's face, nurses can be more sensitive to caregiver's experience and assist caregivers in assessing their caregiving situation. In some cases nurses' knowledge of caregivers experience may help them to support the caregiver in dealing with limitations that cannot be prevented or remedied, such as further decline of the care recipient.

Preparing families and providing information regarding what can be expected may ease the uncertainty experienced prior to the placement of a family member in a long term care setting and the discomfort following. Making clear when the event is expected to occur, how long it may take, and that only a short time is given when the call is made indicating a bed is available, would assist caregivers to live with the uncertainty they experience.

Nurses must be alert to those family caregivers who have little experience in this environment, realizing that they might have a difficult adjustment. Increased familiarity of the long term care environment may reduce the shock experienced by some caregivers after placement. Invitations by the care facility to family caregivers to take part in a function such as a social tea, prior to placement before emotions are high and many things are occurring at once, could prove beneficial, particularly if introduced to other family caregivers and staff.

Orientation sessions for family caregivers just after placement would be highly beneficial. Families need to learn the routines, be clear on what is expected of them, and understand what can be expected from the care recipient in response to placement. This would provide an opportunity for nursing staff to introduce themselves, and also for families to be introduced to other family caregivers new to the long term care facility. Realizing that many families are not aware of the location in which their family member will be placed until a bed becomes available, advance preparation may not be feasible.

Due to a limited number of long term care beds family caregivers are often encouraged to provide care in the home for as long as it is possible before considering

long term care. This expectation will likely remain as the population ages, and more demand is placed on these facilities. Nurses are often the "gatekeepers" of these facilities. Thus, it is imperative that they have an understanding of what the family is going through in order to keep the care recipient at home. In addition they must better understand how families come to this decision, which usually is not made lightly. Once a caregiver comes to this decision they have undergone a realization and shift in their view of how they can caregive. Nurses must be aware that changes have occurred and that contacting, and going through placement is a part of a larger process.

Another nursing role is that of patient and family care advocate. Advocacy and support are certainly needed as family caregivers face the difficult task of caring for a family member with Alzheimer's disease in the community as they are "facing limitations", through making the decision to place, and while "finding their way " after placement has occurred. By receiving information and support throughout the process of placement family caregivers may be assured that they will survive this ordeal, and that others before them have faced a similar situation. For example, many nursing staff may assume that a decrease in visits may indicate less interest. However in this study, it is identified as an aspect of redefining one's caregiving role, and in no way suggests abandonment. In addition, with an increased understanding of the grief experience that caregivers encounter, nurses can gain a better understanding of the persons they serve. They will also be better equipped to establish partnerships with caregivers to foster healthier outcomes as a caregiver's health and well being is vital for all concerned.

Implications for Nursing Education

In the recent past care of the elderly and caregivers has been given more emphasis in basic nursing education. Ultimately it is hoped that this research study will add to nursing's knowledge base and improve nursing practice in the area of family caregiving, placement, and Alzheimer's disease. To begin, nurses whether students or practitioners in the field, must first be taught about the transitions family caregivers will experience in their journey of caring. This in turn will foster a sense of support, responsibility, and interest in this area which will ultimately benefit family caregivers in general. Understanding and anticipating the emotional response many family caregivers experience immediately after placement, and the anticipatory grief they describe throughout will further enhance nursing's ability to support family caregivers. By providing guidance and support family caregivers can be assured that this is an aspect of the adjustment, that their feelings are normal, and that with time it will improve.

Nurses need to understand that caregiving is not a static role, but a role which is individually redefined depending on the context, the individuals involved and their life experiences. In turn, barriers and bias can be examined and lifted in terms of nursing's expectations of family caregivers, fostering a healthy partnership.

Implications for Nursing Research

As this is a grounded theory study, it is hoped that research in this area will continue and this study will provide direction. Although much is being uncovered about family caregiving and Alzheimer's disease, much still needs to be understood in the area of family caregiving and role transitions, the trajectory involved in

considering placement, the impact of placement on family caregivers, gender and relational differences, and family caregiving in a long term care setting.

The findings in this study point to several areas in caregiving which require further study. One is the challenge for the caregiver of releasing control, to staff in a long term care facility, and how this relates to the transition experience. Further examination of the caregiver's perspective of control during the transition from caregiving in home to caregiving in a long term care facility will contribute further knowledge in this area. Secondly, many studies in the literature indicate that stress and burden continue after placement has occurred. Future research is needed to examine changes in burden and stress over time as well as caregivers' ability to come to terms with the long term care move.

The intent of qualitative research is not to generalize findings to the larger population but rather to shed light on and uncover what is experienced by participants, at that particular time. All in this study were white middle class individuals from an urban setting. Not captured in this study, but warranting further study is the experience of persons from other cultural backgrounds, from a rural location, and the unique experience of wives, sons or non family informal caregiver of the care recipient. Also of interest is whether this grounded theory is relevant to other caregivers, such as those caring for persons with other health concerns, or caring for children and having to consider placement in a long term care or acute care facility.

Conclusion

In this study the process of "redefining one's caregiving role" was uncovered based on interviews with 10 family caregivers who had placed a family member with Alzheimer's disease in a long term care facility within the last 13 months. The process portrays the transition family caregivers undergo before, during and after placement. Within the context of this study the findings suggest that family caregivers while providing care in the community face limitations in the areas of health care, the care recipient, themselves, family or community. Placement is considered after caregivers reach a point when they realize that the care recipient's needs outweigh their caregiving abilities and resources, and issues of safety arise, brought forth by a crisis event or series of events. Uncertainty is experienced in coming towards and following through with the decision of placement and it is a highly emotional time for caregivers. The long term care environment, care recipient's response, and the decision itself, influences the caregiver's ability to come to terms with placement of a family member in a long term care facility. Throughout the transition caregivers are redefining their caregiving role which involves redefining one's caregiving focus and one's level of involvement, and is made clearer as the caregiver comes to terms with the placement. After one's caregiving role has been satisfactorily redefined, routines can be established. However the grief experienced by caregivers is ongoing, and influenced by change and decline in the care recipient.

The conclusions drawn from this study are confirmed in several other research studies. However, this study is unique in attempting to provide a comprehensive view

of the transition experienced by family caregivers of person's with Alzheimer's disease when a family member is placed in a long term care facility. By shedding light on this area health care professionals will be better prepared to assist family caregivers through this transition, and further study can be done. Family caregivers will also benefit from understanding what they are going through, and recognizing that others have traveled this path before them. For some this understanding may ease the discomfort and difficulty associated with this transition and assist them achieve a healthier outcome. In turn nurses can better understand the valuable and important role caregivers play in the community and in a long term care facility.

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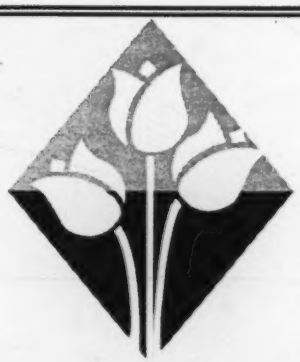

Have you been caring for a family member with Alzheimer's Disease who has entered a long term care facility in the last year?

If so, and you are willing to talk with a nurse about your experience, please call Moira at 417-6974. You will be interviewed once or twice as part of a research study.

Appendix B

Consent Form

Project title: Placing a family member with Alzheimer's disease into a long term care facility.

Researcher : Moira Bazin
MN student, 464-7096
Faculty of Nursing,
3rd Floor
Clinical Sciences Building
University of Alberta, T6G 2G3

Advisor: Dr. Anne Neufeld
Professor, 492-2699
Faculty of Nursing
5-134 C
Clinical Sciences Building
University of Alberta,

The purpose of the study has been explained to me. If I agree to be in the study, I may have to give up to 2 one hour taped interviews. I do so voluntarily, and can quit at any time. I do not have to answer or discuss anything I do not wish too. Being in this study will not in any way influence the care being given to my family member by any agency.

I understand there are no known benefits (i.e. money) for my participation in this study. There is the risk that some questions may bring out certain feelings that are uncomfortable. If it is found that I am having difficulty dealing with my feelings, the researcher will give me the phone numbers of someone who might be able to help me.

I understand that my identity will be protected. My real name will not appear on the data, instead a code name will be used. As well much of the information will be pooled with the other interviews to further protect my identity. I understand that the tape recording of my interview will be typed out and the audio tape and written copy will be kept for at least seven years. The notes, computer discs, and codes will be kept in a locked filing cabinet. Only the researcher will be able to open the filing cabinet.

I am aware that the information I give in this study will be kept on file at the University for at least seven years. If my information is used by other researchers in the future, I understand that proper ethical clearance will be obtained to protect my privacy.

I have been asked if I have any questions about this study and have had them answered. I understand that a copy of this consent will be given to me today. I can contact the researcher whenever I wish with questions or concerns about the research study.

I would like to have a copy of a report on the research findings; Yes ___, No____

Signature of participant _____ Date_____
Signature of witness _____Date_____

Appendix C

Interview Guide

Interview # 1. Guiding Questions

1. Tell me how you came to providing care for your family member?

2. How did you come to consider placement?

3. After you began considering having your family member enter a long term care facility, were there any changes in your life? If so please tell me about them.

4. What were your feelings and thoughts as placement began to become a reality?

5. Did your caregiving change after your family member entered long term care? If so, in what ways?

6. What, if anything, is different now as compared to what you experienced over the first few months after _____ moved into the nursing home?

7. In what ways is caring for _____ in the nursing home similar or different from being a caregiver at home?

8. Is there anything that you would like to tell me regarding a) your experience in placing _____, and b) your experience in being a caregiver for someone in longterm care.

Interview # 2

1. Were there any particular events that influenced your experience with placement?

2. What were your feelings and thoughts about your experience at the time?

3. You mentioned that you experienced _____, about having to make this decision, did this change? If so in what ways?

4. Tell me about how things changed as you were making this decision.

6. Were there any people who had a particular influence on your experience in placing your family member? If so, who were they, and how did they influence you?

7. When did you start to feel the adjustment to placing your loved was over, or is it?

8. Was this something you and your family member discussed before?

9. Tell me how your caregiving has changed since placing _____.

10. Tell me what was helpful during this experience, what was unhelpful?

11. Did you think about what this experience would be like ahead of time? If so what measures did you take to prepare yourself?

12. Have you any suggestions for others in the same situation?

13. Is there anything else that you would like to tell me about your experience?

Demographic Questions

1. How long having you been caring for your family member.

2. What relationship are you to your family member? i.e. spouse, child, niece or nephew

3. In what year were you born?

4. In what year was (CR) born?

5. Are you currently employed? Yes ____ No_____, If yes full time or part time.

6. Current Occupation, or Former Occupation.

6. Marital status? Married, Married but Separated, Single, Divorced, Widowed

7. What was _____ occupation, your spouses occupation?

8. Do you have other roles and obligations? i.e. mother, grandmother, volunteer work etc.

9. What is the diagnosis used to describe _____ poor mental functioning? Was ____, ever told he or she had Alzheimer's disease?

10. In what long term care facility is your family member presently housed?

11. How long ago did they enter the long term care facility?

Appendix D

Participant Information

Informant	Age	Relationship with care recipient	No. of Months in care at 1st interview	No. of Months in care at 2nd interview	Age of care recipient	Type of facility care recipient housed	Employment status of caregiver	Placement considered a planned event	Deterioration of care recipient after move	Care recipient recognizes caregiver
1	73	husband	4	6	74	locked unit	retired	yes	yes	inter-mittent
2	82	husband	10	12	80	general unit	retired	yes	no	yes
3	44	daughter	8	10	76	assisted living settings for person's with AD	full time	yes	yes	yes
4	50's	daughter	5 wks		86	special care facility for person's with AD	full time	yes	no	yes
5	49	daughter	5	6	80	locked unit	part-time	no	yes	yes
6	62	daughter	11	12	90	cognitively impaired unit	retired	no	yes	yes
7	47	daughter	4	6	84	general unit	part-time	yes	yes	inter-mittent
8	late 40's	daughter	13	13	78	locked cognitively impaired unit	full time	no	yes	yes
9	57	daughter	2	2	84	general unit	full time	no	no	yes
10	52	daughter	5	5	89	cognitively impaired unit	retired	no	yes	inter-mittent